

“By talking about it we can make it a positive thing”:

Autistic people negotiating identity and understanding in discursive contexts

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## **Abstract**

Broderick and Ne'eman write that in the early 2000s autism took hold of “the public imagination internationally” becoming a “popular cultural obsession” (2008:462). Autistic people are discursively constituted within this cultural context. My goal in this research has been to better understand the dominant and counter discourses constituting autism, how young autistic people themselves embody discursive locations throughout their lives, and how they negotiate the intelligibility of their subject positions. Previous research has looked at how autistic people negotiate diagnoses, whether they feel understood, the discursive positions they embody, and how discourse constitutes their subjectivities. Using a qualitative exploratory research design, I conducted semi-structured interviews with four individuals, ages 22, 23, 23, and 26, who identified as having been labelled as autistic at some point in their life, either by themselves through a self-diagnosis or by a medical professional. I employed thematic analysis and emerging themes were: *Diagnosis*, *Intelligibility*, *Terminology*, *Medicalization*, *Identity*, *Life Course*, and *Internalizing Responsibility*. This research is significant in its contribution to representations of autistic people’s perspectives. It focuses on people in their 20s and people who do not have formal diagnoses, who have been underrepresented in research. The present research also builds on previous literature by addressing when autistic people lack language to talk about oppression, how they internalize responsibility for social interactions, and their reflections on their futures.

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## **Chapter 1: Introduction**

There has been a proliferation of stories about autism throughout culture, in medicine, research, education, and in autism awareness and advocacy organizations (McGuire 2016). McGuire argues that these stories are all interconnected in their formation of an overarching dominant discursive constitution of autism (McGuire 2016). Discourses are defined by Goodley as “regulated systems of statements, ideas and practices, providing ways of representing particular forms of knowledge” (Goodley 2011:103). They are enacted through language, with the ways we speak conveying and legitimizing discursive norms (Goodley 2011). Language also changes meaning in different discursive contexts (St. Pierre 2000). Discourses produce binaries, constructing one category as the opposite of the other, with each supporting the discursive positioning of the other (Goodley 2011). Discourses are continuously constructed and maintained through repetitions of normative performances, in addition to counter discursive performances of non-conformity (McGuire 2016). The most powerful proponent of the dominant discourse of autism is Autism Speaks, an organization widely criticized by the neurodiverse advocacy and autistic communities for perpetuating the view of autism as pathology, and thus failing to represent how many autistic people see themselves (Broderick and Ne’eman 2008).

Within the dominant discourse, autism is framed as an illness of abnormality (McGuire 2016). Instead of having their differences perceived as unique, and potentially positive, personality traits with value, individuals are constituted through a medically pathologizing discourse, with autistic traits framed as deficits in need of treatment and a potential cure (Bumiller 2008). Combined with persistent and severe social stigmas surrounding autism, this medicalizing view has a very negative impact on the everyday lives of autistic subjects, as demonstrated by fears individuals express around being accepted by others and their attempts to

pass as neurotypical (Baines 2012). People embody discursive locations, constructing their knowledge of themselves and their behaviours around the ways they feel knowable as they are constituted through discourses. Post-structuralists assert that subject positions, identities imposed and taken on by individuals, are continuously performed and constituted through discourse (Goodley 2011; St. Pierre 2000). People only feel knowable through certain discourses because they are reproduced and pervade our entire lives through medicine, school, work, and many other institutions (Goodley 2011). This can be seen particularly clearly in discourses constituting autism, through medicalizing institutions perpetuating the view of autistic people as other. This perspective is internalized by autistic people as their subjectivities are constituted through discourse by these institutions (McGuire 2016). Dominant discourses, such as that promoted by Autism Speaks, are naturalized and so counter discourses are unintelligible, as are the people who embody them (St. Pierre 2000). Despite the cultural dominance of medical ways of thinking about autism, many people have been speaking out from counter discursive locations, expanding intelligibility. McGuire argues ideas and stories from autistic individuals can contribute to a counter discourse that challenges dominant ideas about autism and disability (McGuire 2016).

Post-structuralism involves the study of discourses and the questioning of what gets taken for granted as being “true.” Post-structuralists study the ways discourses constitute people’s experiences and subject positions. The study of discourses also involves looking at how they are contextual and always in flux (Goodley 2011; St. Pierre 2000). Employing a post-structural framework, my research explores how four individuals, ages 22-26, who identify or have been labelled as autistic negotiate intelligibility, or being understood, through their performance of subject positions as well as discourses, that is, ways of thinking and talking about autism, they take on and embody. I also look at how these individuals’ lives exist within these discursive

contexts. The reason for studying this particular age group is to look at subjectivity among autistic people who are transitioning from childhood to adulthood, and may be becoming more independent, thus developing social and cultural connections outside of their families. This means they are possibly gaining more access to counter discursive narratives, if they have not accessed these perspectives already. Additionally, I wanted to study the ways in which these discourses may be contextually situated, with this age group likely having had a greater variety of experiences than younger people through which their differences were discursively constituted. For example, three out of my four participants were diagnosed at a young age, growing up within particular discursive locations and then learning new ones when they were older. Through narrative interviews, I asked participants open-ended questions surrounding the following key research questions:

- How do autistic individuals construct subject positions around their views about conformity and non-conformity?
- How do these individuals define and perceive neurodiversity and differences in identity and expression?
- Do they believe their constructed subject positions are understood by others? How do they describe the experiences of being understood and misunderstood?
- Are these beliefs and experiences context specific? Do they change over time or according to social context? If so, what differences have these individuals experienced?

To explain my decision to use the term “autistic” instead of “having autism,” I am referencing Sinclair’s argument, as cited by McGuire, that autism is not something a person has, but is part of that who that person is. Saying that someone “has autism,” instead of “is autistic,”

perpetuates the belief that autism is something bad and never something that would be part of someone's identity (Sinclair 1999, as cited by McGuire 2016). Previous research with autistic people also demonstrates that "autistic" or "on the autism spectrum" is the preferred terminology (Kenny et al. 2016). In discussing participants' narratives, I make sure to use the same language around autism that they use themselves, to be respectful of the terminology each participant prefers. Sometimes participants would use different terminology to refer to themselves and others throughout the interviews so my language sometimes changes.

It is also important to note that the language of "autistic people" and "the autistic community" is not in line with a post-structural framework. Post-structural theory on subjectivity demonstrates that describing a person as "autistic" does not reflect the complexity of their experience. Within discursive contexts they are constituted as autistic in a multiplicity of ways and sometimes their experience exists between and outside of these constituted subjectivities (Goodley 2007; St. Pierre 2000). However, I use this language because, as humanist discourse is dominant and naturalized, this is how my participants talk about themselves (St. Pierre 2000). I will also use the term "identity" as one of the themes in my results for this same reason, but in discussing this theme I will focus on theory of subjectivity. In the theory section of my literature review, I will discuss in more depth post-structural theory on subjectivity and how this differs from the concept of identity.

In the rest of this thesis, I will outline my theoretical framework, looking first at theoretical analyses of disability through a post-structural lens by Goodley (2011) and McGuire (2016). I will then focus more specifically on theoretical analyses of autism, drawing primarily from Broderick and Ne'eman (2008), Bumiller (2008), Goodley (2011), McGuire (2016), Straus (2013), and Tremain (2005). This will be followed by a description of previous qualitative

research with autistic individuals that looks at medicalization, self-diagnosis, identity, discourse, intelligibility, coming out, and passing. I will then outline my methodology, including sampling, data collection, and data analysis. At the end of the methods chapter, I will briefly introduce the four participants. Following this, I will discuss the data and the themes that emerged through data analysis, some of which were related to general issues and topics that guided my research questions, and some of which suggested new themes. After the results chapter, I will connect results to theory and previous research in the discussion chapter.



## Chapter 2: Literature Review

Autism as a diagnosis and identity exists within multiple discursive contexts that contest its meaning for autistic individuals and society as a whole. Broderick and Ne'eman write that in the early 2000s autism took hold of “the public imagination internationally” becoming a “popular cultural obsession.” As such, the phenomenon of autism underwent processes of discursive (re)constitution (Broderick & Ne'eman 2008:462). Autistic people are discursively constituted within this cultural context.

To look at how autism is constituted, it is necessary to first outline post-structural disability theory and discuss theories around autism. This discussion will then focus on post-structural theory of subjectivity, discourse, and diagnosis. This theoretical discussion will be followed by a description of previous research on autistic people's experiences.

### OVERVIEW OF DISABILITY THEORY

The concepts of disability and who is constituted as a disabled subject are rooted in the dominant discursive binaries of normalcy and abnormalcy. Post-structuralists work to deconstruct these binary discourses and look for discursive resistance through renaming and resignification, as discourse shapes how we think about ourselves and others (Goodley 2011). McGuire asserts that disability is only intelligible in the dominant discourse as deficiency that needs to be protected against (McGuire 2016). Genealogical research shows many discursive shifts around ideas of illness and impairment throughout history (Goodley 2011).

Post-structural theorists consider medicalization to be a way bodies and subjects are regulated. Goodley traces how nation states have employed discursive power/knowledge to regulate individuals constituted as disabled since the 1700s (Goodley 2011). Knowledge is interconnected with discursive power relations, and so dominant discursive knowledges are naturalized to the point where their legitimacy often goes unquestioned (St. Pierre 2000). Sites of

regulatory power/knowledge include health sciences, such as psychology, as well as institutions, and interventions developed within these institutions (Goodley 2011). As medicalizing discourse is naturalized, it functions to legitimize regulatory institutions and maintains the power/knowledge of the medical professionals, who are deemed experts (Goodley 2011). Forms of regulation include interventions attempting to change those deemed non-ideal, institutions keeping them separate from society, and controls like sterilization trying to prevent them from existing (Goodley 2011). In particular post-structural theory can be used to analyse the discursive constitution of autism in society, and the experiences of autistic people.

## POST-STRUCTURAL THEORIES ON AUTISM

It is helpful to start by discussing what autism is, from a post-structural perspective. McGuire asserts that autism is not a clear and specifically definable thing, but is instead always shifting in its possible interpretations and culturally constructed meanings (McGuire 2016). This perspective highlights the complexity and fluidity of concepts such as disability, difference, normality, and abnormality. Broderick and Ne'eman say that the dominant discourse constituting autism as an illness takes root in and reproduces a dualism of normalcy and abnormalcy (Broderick and Ne'eman 2008). McGuire describes how these “discursive categories and subjectivities govern the bodies and minds of people—they function to limit the ways people can (are permitted to) move, think, act, and exist in the world” (McGuire 2016:72). Rather than permitted, one could say that only certain ways of being in the world are intelligible, because there is not a person or group giving permission. These norms pervade and are embedded in society through dominant discourse and render non-normative ways of being unintelligible. Diagnostic classifications, such as Autism Spectrum Disorder, especially as they are constituted

around ideas of normalcy, produce and regulate the ways people view themselves and perform subjectivities.

McGuire argues that “within the dominant contemporary discursive spaces of advocacy, to live with autism is to long for life without it” (McGuire 2016:194). This view of autism constructs autistic people as waiting to be saved by normative society from their supposed non-normativity (McGuire 2016). She argues that autistic individuals are thus discursively constrained from claiming and embracing the subject position of “being autistic,” as autism is constituted in dominant discourse as an illness one has, making one’s subject position “a person with autism” (McGuire 2016:7). Within medical discourse, people are socialized to regulate themselves, seeking to be viewed as “normal,” and therefore protected from ableist oppression. This is connected to people making themselves intelligible and governing themselves within the context of dominant discourses (McGuire 2016; Vakirtzi and Bayliss 2013). The example of a person constituted as autistic regulating their behaviour to fit social norms demonstrates what Foucault calls “disciplinary power,” as discipline and regulation are taken on by the individual (St. Pierre 2000). Interestingly, McGuire tells us that what autism advocacy organizations label as signs of pathology are often behaviours that are “both ‘too much’ and ‘not enough’” (McGuire 2016:95). This can be seen in how autistic people are often pathologized for not meeting the specific balance of rationality and emotionality constructed as normal. Straus asserts that many psychiatric disorders function to diagnose expressions and behaviours that, at certain levels, would be considered normative, but are constructed as deviant when they are taken too far past this line of normalcy (Straus 2013).

Broderick and Ne’eman assert that the medical discourse of illness and intervention has discursive dominance (2008). Discourses shape how people talk and think about people and

phenomena, thus affecting their very existence in culture. The discursive production of diagnoses, such as those in *The Diagnostic and Statistical Manual of Mental Disorders (DSM)*, creates subjectivities and divides people into categories of “normal” and “deviant.” McGuire draws attention to the construction of autism by mainstream advocacy discourse as a threat to society as a whole, threatening normality (McGuire 2016). She asserts that because of this, those who are diagnosed as autistic often face violent oppression (McGuire 2016).

People who are marginalized in multiple ways, such as being autistic people of colour, often experience more oppression within dominant discourses that privilege neurotypicality and whiteness (Goodley 2011). People’s experiences of disability, as well as any kind of non-conformity to dominant discursive norms, are closely connected to sexuality, gender, race, and class. McGuire writes that ableism affects individuals differently based on intersections of subject positions and thus disability is socially experienced in different ways (McGuire 2016). For example, Lewis talks about gender disparities in access to formal diagnoses. In her study of people who self-diagnosed, 44 percent were women, while formal diagnosis rates show Autism Spectrum Disorder as being 4.5 times more common for men (Lewis 2016). This suggests that autistic women are likely underdiagnosed, which is largely due to gender stereotypes. There is a lot more that can be said about gender and autism, but this is outside the parameters of this thesis topic. Subjectivity, discourse, and diagnosis are key topics in my research, so the remainder of this theoretical discussion will focus on post-structural theory around the constitution of autistic subjectivities as well as discursive constitutions of autism and autism diagnosis.

## SUBJECTIVITY

The central focus of my thesis is individuals and the way they are constituted in subject positions within discourses of autism. In modernist theory this is referred to as identity, but the

concept of identity is troubled in post-structuralism. Post-structural theory demonstrates ways in which people are not categorizable in the way modernist theory has purported, with identities always in flux, being continuously performed by individuals. St. Pierre also critiques the way modernist discourse groups people together while overlooking their differences (Goodley 2007; St. Pierre 2000). People are always constituted into subject positions which shape their experiences, and they are constrained by the categories they are discursively constituted within. They are limited to these categories by the discourses they have access to (Goodley 2007; St. Pierre 2000).

People perform their constituted subjectivities, move between them, and resist them, but while people may resist categorization in some ways, they cannot completely exist outside of it. This is the extent to which subjectification shapes our lives and experiences (Goodley 2007). Because people's sense of identity and experiences are shaped by subject positions, they can resist by taking on and rejecting different subjectivities, and post-structuralists say this ability to move between subject positions is where people have agency. Furthermore, changing subject positions is a form of agency and resistance because this changes the discourses people are constituted within, so they can move between dominant and counter discourses (St. Pierre 2000). For example, taking on the subjectivity of "a neurodiverse person" after previously being constituted as "a person with autism" would provide different experiences, language, and meaning for the individual. The discursive constitution of subject positions means that subjectivities can provide meaning to people's experiences, which helps explain why identity is so important to people (St. Pierre 2000). The post-structural view of subjectivity and the way subjects are constituted is more helpful than a modernist perspective for understanding the experiences of individuals constituted as autistic in discursive contexts. For example, post-

structuralism is more helpful in explaining tensions autistic people express around their constituted subject positions.

Post-structuralism has been critiqued by people who emphasize the importance of identity politics in activism, which includes the neurodiversity movement. St. Pierre addresses this with the feminist movement and people's wish to hold onto an identity category of "women" as a fixed identity. She describes Butler's assertion that questioning "women" as an identity and classification creates a multiplicity of potential meanings, thereby broadening intelligibility, and this is where agency can be found (St. Pierre 2000). Tremain describes the way the disability rights movement has been based around the subject position of being disabled, and argues that identity politics can be limiting because, as was mentioned earlier, individuals are constrained and governed through subject positions, whether constituted through dominant or counter discourses (Tremain 2001; 2015).

## DOMINANT DISCOURSE OF AUTISM

The dominant discursive construction of autism is the focus of McGuire's book, *War on Autism*. Drawing on Hacking, McGuire writes that as "contemporary stories of autism" help construct discourse; they "are, in other words, functioning to constitute what autism is and can be" (McGuire 2016:11). Tremain describes how discursive classifications organize people based on how they exist in relation to constituted norms, and so construct the ways people see themselves and how they are organized in society. This awareness of one's behaviour and experience in relation to norms is a subject's "conscience or self-knowledge" (Tremain 2005:6).

Normalizing practices are offered within culture to individuals, as they are encouraged to change themselves. People are expected within dominant discourses of disability to want to change and to accept these forms of normalization (Tremain 2005). McGuire describes how

people attempt to perform what dominant discourses constitute as normative, policing their thoughts and behaviours (McGuire 2016). Those who are non-conforming become medicalized within scientific and psychological discourses and have their differences devalued as merely part of a pathological condition. Baines draws from Brownlow, discussing these normalizing practices and interventions, which frame autism as “a deficit rather than a difference” (Baines 2012:549). This is not only a problem because of the impact on how autistic people view themselves, but also, as discussed by McGuire, has serious consequences for autistic people’s rights and safety (McGuire 2016).

## COUNTER DISCOURSE AND THE NEURODIVERSITY MOVEMENT

While this dominant discourse is deeply rooted in dominant Western culture and thus shapes most people’s views, autistic and neurodiversity activists have been spreading counter discourses of autism. McGuire asserts that the expression and sharing of counter discourses, such as through stories from autistic individuals, can create more awareness of different ways for autism to exist culturally (2016). This can broaden intelligibility for autistic people, with a multiplicity of narratives rendering their ways of living and thinking more visible. However, she reminds us that, while narratives alternative to the dominant stories about autism do exist, dominant narratives are commonly held as objectively true while counter narratives are often disregarded (McGuire 2016). The dominant discourse gains its strength from its attachment to science and medicine, which are powerful institutions in our society (Broderick and Ne’eman 2008). It is important and significant to note that the dominant discourse constituting autism as an illness is primarily rooted in the non-autistic community, whereas the counter discourse promoting neurodiversity and constituting autism as difference is rooted in the autistic and neurodiverse community (Broderick & Ne’eman 2008). Those representing the dominant

discourse are legitimized as authority figures, and so they are able to devalue the perspectives of autistic individuals and anyone questioning dominant narratives of disease and normalcy (McGuire 2016). Broderick and Ne’eman argue this discursive struggle is so critical because the human rights of autistic people are at stake (Broderick & Ne’eman 2008).

McGuire asserts “disability—its meaning and thus its very materiality—is made and remade, rhetorically and interactionally, between all of us who have a body, all...who live and participate in the making of culture” (McGuire 2016:18). This ability to contribute counter discursive perspectives to the cultural conception of disability is a powerful site for resistance. The neurodiversity movement works to promote a counter discourse of autism along with other mental and neurological differences, questioning the supposed legitimacy of medical discourse and the pathologizing of non-conformity. In her article “Quirky Citizens: Autism, Gender, and Reimagining Disability,” Bumiller argues this is ultimately a social movement about issues of normalcy and broadening intelligibility. Her assertion that autism “is in fact medically defined by an inability to understand social conventions” (Bumiller 2008:976) highlights a connection between social norms, unintelligibility, and disablement. While the counter discourse of neurodiversity is important for disrupting dominant discourses of autism, St. Pierre explains that we must continue critiquing our language, recognizing the way language in a counter discourse can still constrain us. Post-structuralists argue that continuing to question subjectivities is how we have agency (St. Pierre 2000). We can see these discourses embedded in advocacy and activism by autistic people.

Disability theory and models of disability influence and are influenced by autistic activism. Activism for and by autistic people is called autistic self-advocacy (Dekker 2000, as cited by Brownlow and O’Dell 2006). In response to the growth of the autistic self-advocacy



movement, some medical professionals have attempted to “construct themselves as the ‘experts’ in autism” (Ward and Meyer 1999, as cited by Brownlow and O’Dell 2006:316). They do this as a way to hold on to their power/knowledge around autism, resisting alternative knowledges coming from the autistic community (Brownlow and O’Dell 2006). As previously mentioned, those whose knowledges and discursive locations are rendered more valid and intelligible have more power in culture than those embodying a counter discourse (Broderick and Ne’eman 2008). This conflict between medical and self-advocacy discourse is at the centre of understanding autism from a post-structural framework. As autism is constituted in the dominant discourse as a medical label, autistic people’s subjectivities are constituted through medical discourse in the form of diagnosis. The counter discursive action of self-diagnosing reframes autistic identity by constructing it as something that can exist outside of medical discourse and institutions. However, some form of diagnosis is still central to performance of autistic subjectivity.

#### POST-STRUCTURAL VIEW OF DIAGNOSIS

Bertilsdotter-Rosqvist describes diagnosis “as an expression of social conflict” (2012:120), something that is in flux as groups shift meanings of diagnosis according to how they perceive illness and disability (Bertilsdotter-Rosqvist 2012). In this way, one could also define diagnosis as the site of discursive conflict around what autism means to different groups, such as medical professionals, the autism advocates discussed by McGuire, and autistic people themselves. Bertilsdotter-Rosqvist argues “diagnostic terms can both challenge and uphold medical authority” (Bertilsdotter-Rosqvist 2012:120). She asserts that the way people contest which subject positions possess the knowledge needed to diagnose demonstrates how diagnosis is a site of discursive contestation. People even contest what criteria or traits are part of autism, and who should thus receive a diagnosis. Bertilsdotter-Rosqvist describes how “professional

expressions of knowledge are challenged by the construction of lay diagnostic standards, such as alternative inclusion criteria,” which exist as lists autistic people publish on Tumblr, other blog spaces, and in Facebook groups (Bertilsdotter-Rosqvist 2012:120). So here you have autistic people helping each other self-diagnose without involving professionals, as this community constructs autism among and for themselves. Besides constructing alternative diagnostic criteria, autistic people construct autism as identity, rather than a deficit (Bertilsdotter-Rosqvist 2012). This is a counter discourse of autism that exists in conflict with the medical discourse, as well as other discourses discussed by McGuire (2016).

The neurodiversity movement seeks to destabilize medical power/knowledges that give medical institutions the ability to constitute people as disabled through diagnosis. Many in this movement promote people taking up labels of difference and non-conformity outside of medical contexts. In a description of what autistic culture could be, as it is created by autistic people, Straus proposes that autistic people could be conceptualized as a political and cultural group, asserting that people should be able to identify as autistic as they wish, rather than through diagnosis constituted within a dominant medical discourse (Straus 2013). Attaining a diagnosis is important for autistic people, as it gives them intelligibility. Bertilsdotter-Rosqvist asserts that it “may provide security by offering a name for an experience; it also bestows legitimacy, and thus social recognition, because it signals that an individual’s talk of his or her experience is taken seriously by others,” (2012:120). The benefits of having a diagnosis mentioned by Bertilsdotter-Rosqvist unfortunately frequently only apply to a formal diagnosis. However, having a self or formal diagnosis can help people find community and solidarity through a shared identity (Bertilsdotter-Rosqvist 2012). Some resources are available to self-diagnosed people, such as

counseling or services from some autism organizations, but autistic people often need a formal diagnosis to access resources like educational accommodations.

An important part of this discussion is critically analyzing the differences in perceptions of medical and self-diagnoses. Autistic people who experience intellectual disability, who make up around half of the autistic population, are more likely to be diagnosed, and diagnosed earlier in life. Meanwhile, among autistic people who are not intellectually disabled “delayed diagnosis is common and individuals may even reach adulthood before they are diagnosed” (Lewis 2016:575). These are the people constituted as “high functioning” within the medical diagnostic discourse. While these people do not have intellectual disability, they are likely to experience mental illnesses that are comorbid with autism. These mental illnesses are exacerbated by the fact that these people often do not understand the reasons for their experiences and are unable to access supports, which is a problem for 50-60% of undiagnosed “high functioning” autistic people (Lewis 2016). People in this undiagnosed group cope with their lack of access to supports and self-understanding through self-diagnosis.

As previously mentioned, the internet is a key tool that autistic people use to learn about autism and form a self-diagnosis (Lewis 2016). This is interesting yet unsurprising, as the internet has become a space autistic people use to find validation and community. Other cultural factors play a part here as well. Lewis asserts that self-diagnoses among autistic adults “have no doubt been influenced by the presence of online support groups and forums, a rise in television characters and media representatives with ASD, and popular biographical books about adult diagnosis of ASD” (2016:575). Socio-cultural factors, and especially use of the internet for education and community building, significantly contribute to the ability of autistic adults to better understand themselves and self-diagnose.

Discussion thus far of subjectivity, discourse, and diagnosis highlights the experiences of autistic people from a theoretical perspective. Now it is important to discuss previous research on how the issues brought up in this discussion are present in the lives of autistic people, which importantly involves autistic people's narratives.

## PREVIOUS RESEARCH

Previous research themes that relate to my own research include discourse, identity, and intelligibility. A more detailed discussion of how these themes are addressed by previous research will be outlined shortly. For my literature review, I am intentionally focusing on previous research with autistic people, rather than their parents, or others who interact with them. This is in response to a trend in autism research to focus on neurotypical people who interact with or care for autistic people, to the exclusion of autistic people themselves (Huws and Jones 2008). This tendency in research has been critiqued by disability scholars and activists. It is important to talk to parents and others about autism as well, but these scholars and activists critique the underrepresentation of autistic people's voices in research. Baines describes how previous studies on autism, such as Huws and Jones (2008), have demonstrated the importance of talking to autistic people about their experiences (Baines 2012). Huws and Jones conducted their study with a group of autistic young people, because they wanted to highlight the perspectives these individuals had about autism, as much of the research at the time focused on parents of autistic people (Huws and Jones 2008).

The research I am focusing on highlights autistic people's narratives. Mogensen and Mason assert that the majority of research on autism has involved a researcher studying autistic people without including their perspectives in the research. Additionally, they argue most research has highlighted deficits in autism instead of holistically representing research

participants (Mogensen and Mason 2015). The importance of conducting narrative research with autistic people themselves reflects Foucault's idea of "subjugated knowledges," which he defines as "a whole series of knowledges that have been disqualified as...insufficiently elaborated knowledges: naive knowledges, hierarchically inferior knowledges, knowledges that are below the required level of erudition or scientificity" (Foucault 2003:7). Foucault asserts that particular knowledges are deemed less valid, and so are the narratives of people who express these "subjugated knowledges" (Foucault 2003:7). As I discussed when talking about the power relations embedded in dominant and counter discourses of autism, narratives that are counter to medical discourses are frequently dismissed (St. Pierre 2000). By focusing on autistic people's narratives, research can highlight knowledges that are often ignored.

Earlier I briefly mentioned themes in previous research that relate to my own research. More specifically, the research I will review covers previous research themes and issues of medicalization and formal diagnosis, self-diagnosis, various aspects of intelligibility, discourse, identity, and the practices of coming out and passing.

### *Medicalization*

Research on medicalization refers to aspects of autistic people's experiences that have to do with receiving a diagnosis, meeting with medical professionals, and experiences with treatments or therapies, which are often referred to by medical professionals as interventions. A nuanced discussion of medicalization is important, as these experiences can be positive, negative, or a complicated mix of both. Previous research looks at formal diagnosis, interventions, and self-diagnosis.

### *Diagnosis in previous research*

A key experience that autistic people share and that relates to all three issues of discourse, identity, and intelligibility, is that of receiving a diagnosis. For autistic individuals this can happen through self-diagnosis or through a diagnosis from a medical professional. Age is significant in when and how autistic people receive diagnoses. Huws and Jones describe how receiving a diagnosis tends to occur later for people diagnosed with Asperger Syndrome, with many people only getting certainty in their diagnoses as adults (Huws and Jones 2008). There has been a lack of research around people's experiences being diagnosed as adults (Lewis 2016). As diagnosis is a significant aspect of the development of autistic identity and integrally connected to discursive context and intelligibility, I spent a significant part of interviews discussing this with participants, and will discuss here the previous research on individuals' responses to receiving their diagnoses.

Huws and Jones interviewed nine people, from 16 to 21 years old who attended a college specifically for autistic individuals (2008). Mogensen and Mason studied five teenagers, ages 13 to 19, taking an ethnographic phenomenological approach and employing thematic analysis. They explain that there has been little research looking at how children and teenagers are affected by the process of diagnosing and the labels they are given. Mogensen and Mason assert that it is important to look at these individuals' lived experiences around receiving a diagnosis, and what their diagnoses mean to them (Mogensen and Mason 2015). They describe how their participants' perspectives around receiving a diagnosis were much more varied than has been illustrated by previous research (Mogensen and Mason 2015). In Huws and Jones' research, individuals reported various responses that they felt upon finding out about their diagnosis, with many experiencing distress and disbelief (2008). Participants expressed both "acceptance and

avoidance” of their autism diagnosis (Huws and Jones 2008:103-104). Despite individuals’ discovery of their diagnosis being an upsetting experience, it was also helpful in providing an explanation and context for life experiences (Huws and Jones 2008). Their findings also revealed that gaining this label or identity could possibly prevent some negative treatment by others (e.g. bullying) by “legitimizing to others why she or he might behave in a certain way” (Huws and Jones 2008:105).

Participants also experienced receiving their diagnosis as both “disruptions and opportunities,” as some felt their life plans had to change, whereas for some this created possibilities through gaining accommodations and services (Huws and Jones 2008:103). The disruption side of this where “there is an uncertainty about the future that calls for a re-evaluation of biography and a reconstruction of self-identity and self-concept” (Huws and Jones 2008:105) is interesting in regards to research on identity and autism. My research follows on this finding by exploring how autistic people might negotiate this change, for those who experience it. This is relevant to processes of negotiating intelligibility and embodiment. Huws and Jones assert that awareness of the autism diagnosis “could potentially assist in the development of a positive self-concept and self-identity” (2008:105). They describe how all participants, regardless of their feelings around learning about the diagnosis, changed their identity in some way. The explanation for feeling different throughout their lives was cathartic for some individuals, while others rejected and distanced themselves from the label (Huws and Jones 2008).

In Mogensen and Mason’s research, young autistic individuals shared how the experience of receiving the diagnosis had positive and negative aspects. Getting the autistic diagnosis brought stigma and different treatment by their neurotypical peers. Yet, at the same time, they gained self-understanding. Realizing they were autistic validated these people’s feelings of

difference, and was thus empowering (Mogensen and Mason 2015). The experience of gaining a label helped them understand themselves in terms of identity, a topic in research that will be discussed more later. This helped one participant by showing him he was part of and similar to a larger community. It helped another, as he appreciated feeling unique (Mogensen and Mason 2015). For one participant, having a label gave him an explanation for things he struggled with, and also gave him the knowledge that there were ways he could cope with and treat things that caused problems for him (Mogensen and Mason 2015). It is important to include this perspective, since autistic people do experience aspects of their autism as disabling and we need to listen to all autistic people's perspectives.

While diagnoses can be helpful for people, we also need to address the stigma and discrimination that can come from a diagnosis. Receiving this label also sometimes increased the possibility of discrimination due to stigma. Interestingly, participants in Huws and Jones' study experienced a mixture of enacted (direct discrimination) and felt (fear of discrimination) stigma, with the differences between these forms of stigma and discrimination often unclear. This demonstrates complexity in the experiences of stigma that autistic people face (Huws and Jones 2008). Mogensen and Mason also talk about stigma as a disadvantage of diagnosing children, because of stereotypes about autism. They describe how through this medicalizing process, these children may be pathologized and have their individuality overlooked, thus reducing them to the label (Mogensen and Mason 2015).

### *Interventions*

In a discussion of diagnosis and medicalization it is also important to discuss interventions and therapies, as they are significant in many autistic people's experiences. I already discussed this notion in reference to theory on autism. For previous research, I will only



touch on intervention and therapy briefly, as it did not come up in my own research, and so I am choosing to focus on other aspects of autistic people's experiences. In Mogensen and Mason's research, a participant described experiencing "intense, early intervention directed by a health professional" (Mogensen and Mason 2015:258). She felt that people were trying to construct and change her identity, in an experience that was confusing to her. She felt that "interactions with others and, in particular, with health practitioners confronted her with ways in which she was different and outside the norm" (Mogensen and Mason 2015:258). In this way, intervention practices directly formed a sense of identity where she felt different from others. This highlights how identity is often imposed on autistic people as a label, rather than constructed on their own terms. Autistic identity can also be gained outside of medicalizing contexts through self-diagnosing, where autistic people have agency.

### *Self-diagnosis*

It is notable that significantly less research has been done with self-diagnosed autistic people (Lewis 2016). Lewis, who analysed narratives of self-diagnosing with a phenomenological approach, describes how participants in a study she conducted had self-diagnosed for 3.25 years on average before receiving a formal diagnosis as an adult (Lewis 2016). Similarly, Bertilsdotter-Rosqvist found that people in her study sought a formal diagnosis after realizing they might be autistic by themselves and with the help of other autistic people (Bertilsdotter-Rosqvist 2012). She took an ethnographic approach, conducting fieldwork that involved observations and interviews with adults at a school for people with Asperger's (Bertilsdotter-Rosqvist 2012). Lewis argues that since autistic people sometimes cannot access a formal diagnosis, medical professionals should acknowledge those who self-diagnose (Lewis 2016).

Lewis researched people's experiences of self-diagnosing to better understand their experiences, including how people may be affected by not receiving a diagnosis as children as well as the reasons for people not getting formal diagnoses (2016). She "aims to empower and understand the experiences of those who feel confident that they have ASD but have been unable or unwilling to seek formal diagnosis" (Lewis 2016:576). I have similar goals with my research. As Lewis notes, self-diagnosed people have been vastly underrepresented in research on autism (2016), and better understanding the experiences of people whose perspectives often go unheard is an important purpose for research.

Lewis found that people who self-diagnosed had similar experiences to those who were formally diagnosed, although they experienced self-doubt, while those with formal diagnoses did not. Additionally, self-diagnosed people cannot access the same resources that formally diagnosed people can, and thus lack important supports (Lewis 2016). Lewis asserts that participants in her research described "finding self-acceptance and understanding of their strengths" (2016:578). People were able to feel this way without receiving a formal diagnosis, which "implies that self-awareness may be more influential than actual diagnosis on reaching this milestone" (Lewis 2016:578). This is an interesting finding, demonstrating the significant impact self-diagnosis can have for autistic people as well as its positive benefits. Another important issue connected to diagnosis and intelligibility is community, especially a sense of connection to others. Participants felt a sense of belonging upon meeting other autistic people, such as online, though some also began feeling more separate from neurotypical people (Lewis 2016).

Looking at autistic people's experiences before they even self-diagnose, when they are not yet aware of their disability, Lewis describes how they often know they are different

somehow and it is not surprising that this sense of difference would lead to harmful feelings around identity. Lewis reports that “participants experienced low self-worth, feelings of inadequacy, and isolation prior to self-diagnosis” (2016:578). Unfortunately, the experience of self-diagnosing can exacerbate these issues, because these people are going through a time of questioning their identities without access to supports (Lewis 2016). Lewis argues that medical professionals should acknowledge the validity of self-diagnosis and work with these individuals, which may include helping them access a formal diagnosis, so that these people can receive the validation and supports they need (2016).

Lewis found that most participants felt positively about their self-diagnosis, but some “indicated that their self-diagnosis was ‘unsettling,’ ‘separating’ them from others, difficult to accept, and made them reflect on their pasts and mourn the loss of ‘not knowing sooner’” (2016:579). This echoes previous research on people receiving an autism diagnosis. Once they started questioning the possibility of being autistic, some would obsessively research autism attempting to confirm whether they fit the diagnosis. They described feeling more and more confident through their research, although described experiencing denial, some of which came from learning negative things about autism (Lewis 2016).

Integral to discussing medicalization and diagnosis in post-structural research is examining the questioning of medical knowledge as superior to autistic self-knowledge, which is illustrated by the acceptance of self-diagnosing in the autistic community. Brownlow and O’Dell argue that this is a way participants in the online discussion group they studied “challenged the dominance of scientific knowledge” (2006:318). Participants believed that medical professionals do not know autistic people the way autistic people know themselves, and so self-diagnosis should be accepted as valid. While people in the discussion group believed in self-diagnosing as

legitimate, they also paradoxically viewed gaining a formal diagnosis as important (Brownlow and O'Dell 2006). This could be due to autistic individuals seeking intelligibility in society as whole, wanting their identity as autistic to be seen as valid. Formal diagnosis is also important because, as recently mentioned, it is necessary to access supports and resources (Lewis 2016).

Participants said they understood themselves better upon self-diagnosing, realizing their strengths and also learning how to cope with impairments arising from autism. Some people were content with a self-diagnosis and did not want to get a formal one, whereas some wanted one for various reasons, such as accommodations and fearing coming out to people and not being believed. People described a personal diagnosis as being beneficial because it helped them understand and explain themselves, which was something they gained, even without getting a formal diagnosis (Lewis 2016). Having this awareness gave them intelligibility by helping them understand themselves.

### *Intelligibility*

Experiences around intelligibility and understanding that previous research focuses on are awareness of being autistic, stereotypes, being disbelieved, intelligibility among neurotypical peers and other autistic people, and how medicalization and diagnosis impact intelligibility. First of all, it is important to talk about what it is like for autistic people to not understand themselves, which some experience when they do not have a diagnosis. For individuals who went for a long time without a diagnosis or knowledge of their autism, Huws and Jones refer to autism as being an “absent presence” (Huws and Jones 2008:102), as it was an integral part of their lives, yet something they were simultaneously unaware of (Huws and Jones 2008). These autistic people could tell and sense that they were different from others, but had no explanation for why (Huws and Jones 2008; Mogensen and Mason 2015). This happens with “disclosure delay,” which

refers to the experience of autistic young people who had been diagnosed as children, but not informed until several years later (Huws and Jones 2008:102).

Autistic self-advocates emphasize the need for autistic people to know about being autistic, so that they can have an explanation for ways they may feel different from others or experience impairments (Mogensen and Mason 2015). One of the participants in Mogensen and Mason's research had experienced "disclosure delay" and was upset that she had gone for a long time without knowing she was autistic, as she had only found out a few months before her participation in the study. She was upset that she just now gained this information that would help her understand herself better, and had gone so long without it (Mogensen and Mason 2015). Even when people know they are autistic and understand themselves, they struggle to be understood by neurotypical people due to stereotypes about autism. Many autistic people even experience being disbelieved when they come out to others.

### *Stereotypes and disbelief*

As previously mentioned, people with self-diagnoses experience self-doubt and problems with people not believing them when they come out. Unfortunately, this experience is even shared by those with formal diagnoses, according to Bertilsdotter-Rosqvist's findings. This happens because of pre-conceptions and expectations people have about autism. The possibility of misunderstanding discourages people from coming out. Participants expressed how neurotypical people, in trying to counteract stereotypes, would try to convince them that they were neurotypical, in an effort to "be nice," since Asperger's is constructed as negative (Bertilsdotter-Rosqvist 2012).

Research from Mogensen and Mason demonstrates that some autistic young people have trouble in their relationships that can be connected to stereotypical views of autism (2015). In

this way cultural views and depictions of autism in the media are directly impacting young autistic people and their relationships. Mogensen and Mason describe how participants would resist negative stereotypes of autism in their identities, speaking out against them in their interviews. They felt that autistic people needed to be better understood in culture. Participant's concerns about being stereotyped and the stigma around autism made them apprehensive about coming out to their peers (Mogensen and Mason 2015).

Despite this, autistic people may negotiate and employ stereotypes and other cultural conceptions of autism in order to construct and perform identity. Bertilsdotter-Rosqvist talks about how cultural knowledges about Asperger's, even if they are deemed to be stereotypical, "may be viewed as cultural resources with which people with Asperger's can identify and to which they can relate—to resist, question, or embrace" (Bertilsdotter-Rosqvist 2012:126). This demonstrates ways that autistic people may attempt to position themselves in relation to various discursive constructions of autism, using stereotypes to gain intelligibility. For example, one participant in Mogensen and Mason's research felt comfortable with people knowing about his autism "and the idea of being different in ways that worked for him socially," such as maybe liking being known as "unusual" (2015:262). In this way, he negotiated intelligibility around other people through constructions and performances of autistic identity and difference.

#### *Intelligibility among neurotypical peers*

Individuals' feelings of intelligibility around their peers can impact how they feel about themselves. One of Mogensen and Mason's participants described how once he made friends and felt accepted among people outside of school, specifically at his church, he changed his perspective and realized he may not be as different as he had thought. Mogensen and Mason explain that "Ian's new experiences outside of school not only enabled him to feel useful and

valued, they had the effect of ‘normalizing’ him as a person” (2015:264). This is really interesting, because it highlights a case where others’ perspectives of this individual shaped his sense of self. He became intelligible to himself upon feeling understood and accepted by others.

Mogensen and Mason found that participants’ understanding of themselves and positive or negative views around their diagnoses were interconnected with their social experiences. Feeling different was upsetting for them if they felt like they were not relating well to their peers, and they were concerned about cultural stereotypes of autism. Participants talked about difficulties they had interacting with their peers as an impairment arising from being autistic. They also felt a lack of control because of emotional regulation difficulties that affected their interactions with others (Mogensen and Mason 2015).

#### *Intelligibility in autistic communities*

While autistic individuals often feel misunderstood by neurotypical peers, connecting with other autistic people is helpful for many of them. Having either a formal or self-diagnosis, can give people a sense that they have a community. Participants in Bertilsdotter-Rosqvist’s study described feeling normal among other autistic people. They were able to gain intelligibility through realizing that there is an explanation for their differences and that there are others like them (Bertilsdotter-Rosqvist 2012). Mogensen and Mason talk about this as well, with one of their research participants disclosing that he began to feel more positive about his sense of self once he found an identity that he shared with others, and especially others he had traits in common with (Mogensen and Mason 2015).

Autistic people often find community online. As the dominant discourse around autism often renders autistic people unintelligible, having a space for their perceptions to be recognized and validated is crucial. Through use of the internet as discursive space, autistic people are

constructing a discursive identity in opposition to “the medical discourse of ‘disordered’” (Ward and Meyer, as cited by Brownlow and O’Dell 2006:316). In this space autistic people are building a culture that represents themselves through their own perspectives about autism (Ward and Meyer, as cited by Brownlow and O’Dell 2006).

### *Medicalization, Diagnosis, and Intelligibility*

Diagnosis and medicalization can be both helpful and harmful for individuals feeling understood and accepted, especially around teachers and medical professionals. A formal diagnosis can have a very direct impact on individuals in how they feel understood by others, in terms of labels and accommodations. One participant in Mogensen and Mason’s research said that he did not feel different from his peers, but that adults did see him as different. He saw this as helpful in some ways because being viewed as different for being autistic was what allowed him to get accommodations in school, for example (Mogensen and Mason 2015). So in this way, an autistic person might not feel different, but they may be aware that they are different in some ways and that being recognized as such is important for access to accommodations and other resources.

Despite these benefits to having an autistic label, the medicalization that often accompanies a diagnosis can also render people unintelligible. Another participant described how she felt made to feel inferior in medicalizing contexts. Mogensen and Mason describe how she “found health professional-client relations disempowering in terms of the professional’s attitude and control over prescribed interventions” where “the professional’s condescending attitude toward her emphasised her inferior status” (Mogensen and Mason 2015:264). She felt this way when medical professionals decided her needs for her and came up with “interventions” for her that left her without control (Mogensen and Mason 2015). This finding is important in



that it highlights just how significantly young autistic people's sense of themselves can be impacted by attitudes from professionals expressed in medical contexts. Medicalization and the perspectives expressed by professionals directly relates to discourse, as the unintelligibility these individuals experience is rooted in dominant discursive constructions of autism.

### *Discourse*

Previous research on autism and discourse looks specifically at subject positions, power/knowledge, and counter discourses of autism. Through Mogensen and Mason's findings, we can see that dominant discourse is embodied in medical views of autism, and how this impacts autistic people. Their research illustrates the ways dominant discourses about autism are experienced by autistic people, and have long-term effects on their self-worth. Part of diagnosis at an early age for many autistic people is "early intervention," which is intended to socialize autistic children to lessen autistic traits that are deemed disabling. Mogensen and Mason describe how one participant believed that early treatment from medical professionals caused her to feel badly about being autistic as a young adult. They connect this participant's experiences to the discursive construction of autism as deficit through the medical definition (Mogensen and Mason 2015). Their findings demonstrate "the extent to which the framing of autism is associated with the ordering of social relations and normative expectations for those with autism" (Mogensen and Mason 2015:267). Thus, their research demonstrates the impact discursive framing of autism can have on the life experiences and well-being of autistic people. While the dominant discursive framing of autism can be experienced by autistic people as oppressive, they also construct their own perspectives of autism, forming a counter discourse. Central to discursive contestations around cultural meanings of autism is the concept of knowledge, and who is viewed as possessing expertise about autism.

### *Knowledge*

Brownlow and O'Dell argue for the importance of “acknowledging the sociocultural production of labels,” because the cultural construction of labels is closely connected to the ableism faced by autistic people (Brownlow and O'Dell 2006:320). They conducted critical discourse analysis by silently observing an online chat group primarily for autistic adults. Their research had two themes: the question of who is considered an “expert” on autism and the use of labels in connection to identity (Brownlow and O'Dell 2006).

Their findings showed people on the autism spectrum viewing other autistic people as more legitimate experts on autism, thus challenging the discursive construction of medical professionals as the most knowledgeable. Participants would argue that these professionals should not be seen as experts in comparison to autistic people themselves (Brownlow and O'Dell 2006). The constructed superiority of scientific knowledge was also brought into question, which connects to the post-structural concept of power/knowledge. Drawing on Foucault, St. Pierre explains how scientific and medical knowledges have become naturalized, and in this way discursive power is linked with knowledge. Power relations can be seen in autistic people contesting medical ideas about autism, and simultaneously in the devaluation of autistic people's views about autism in comparison to more legitimized medical knowledges (Brownlow and O'Dell 2006; St. Pierre 2000). Bertilsson-Rosqvist's participants' narratives also dealt with issues of who is regarded as possessing “true” knowledge. However, Bertilsson-Rosqvist points out that the emphasis on those with diagnoses as possessing knowledge excludes autistic people who are not diagnosed (Bertilsson-Rosqvist 2012).

Similar to Brownlow and O'Dell's findings, these narratives call for recognizing autistic people's knowledge of autism as legitimate, though they also point to professional knowledge as

being important. Participants viewed “experienced-based knowledges” as “an essential complement to professional knowledge” (Bertilsdotter-Rosqvist 2012:126). They expressed that they were the ones with the direct knowledge and felt that should be recognized. However, they also expressed concern around finding someone with supposedly enough expertise to give them an official diagnosis, which demonstrates some ambivalence in feelings around the role of experts (Bertilsdotter-Rosqvist 2012). Bertilsdotter-Rosqvist suggests that this combination of professional and experiential knowledge may be regarded as a necessary part of larger counter-discursive aims of gaining full recognition of the legitimacy and validity of autistic people’s knowledges of their own identities (Bertilsdotter-Rosqvist 2012). This is interesting in that it demonstrates the complexity of an autistic counter-discourse, and the negotiation autistic people must engage in as they challenge the dominant medical discourse.

### *Counter discourse*

In research with autistic communities online language used by groups was different from mainstream culture and the dominant discourse of autism, which is interesting as meaning is communicated through the terms we use. For example, people called non-autistic people “neurologically typical” instead of “normal” (Dekker 2000, as cited by Brownlow and O’Dell 2006:316). This terminology disrupts the discursive construction of autism as “abnormal” and, as Brownlow and O’Dell argue, destabilizes the idea of normalcy to the point of reversing it (2006). Within this space, autistic people construct their identities as positive and are able to see themselves as part of community, rather than an “other.” Interestingly, Brownlow and O’Dell find that in this space neurotypical people are instead constructed as the “other,” and even constructed negatively. They argue that this dichotomous view of autistic as positive and neurotypical as negative was in response to these individuals feeling part of a safe space, as well

as a way of coping with negative views towards autism in primarily neurotypical culture. People in this discussion group also rejected the discursive construction of autism as disability (Brownlow and O'Dell 2006).

Participants in Bertilsdotter-Rosqvist's research also critiqued diagnostic criteria for focusing largely on difficulties, although this is not to say that difficulties should be ignored. They wanted there to be a focus on autistic people's strengths as well as difficulties with autism. In this way, participants questioned diagnostic knowledges, and expressed that they possessed knowledge of themselves that should be included (Bertilsdotter-Rosqvist 2012). Bertilsdotter-Rosqvist specifically studied people identified as having "high functioning autism" or "Asperger syndrome," who had mostly been diagnosed as adults. Her analysis focuses on how her participants talked about diagnosis, to explore how they interpreted their diagnoses from their discursive position of being autistic people (Bertilsdotter-Rosqvist 2012). She also talks about her participants' construction of the "counterhegemonic discourse of autistic normalcy" (Bertilsdotter-Rosqvist 2012:120). In this way autistic activists construct their own concept of normalcy for their own community. Bertilsdotter-Rosqvist problematizes this counter discourse of autistic normalcy, as it can still exclude any autistic people who do not conform to the alternative view of what is "normal" for autistic people (Bertilsdotter-Rosqvist 2012). This is an example of how a community that tries to be inclusive of a particular group of non-conforming people can end up being exclusionary in harmful ways. Constructing an alternative identity for autistic people still has the potential to render some people unintelligible.

### *Identity*

Earlier I discussed post-structural critiques of the concept of identity, and how the concepts of subjectivity and subject positions are more helpful for understanding the complexity

of how people's experiences are constituted within discourse. However, much of the previous research with autistic people makes reference to identity, so that is the language I will use for this section. Previous research on identity construction among autistic people has found that how people view being autistic, such as negatively and positively, is dependent on both discursive and social contexts (Griffin and Pollak 2009; Mogensen and Mason 2015; Parsloe 2015). Research has also explored how dominant and counter discourses a person is constituted within impact how they view being autistic (Bagatell 2007; Baines 2012; Bertilsdotter-Rosqvist 2012; Brownlow and O'Dell 2006; Jones et al. 2015; Parsloe 2015). Importantly, agency is a central issue, and many people construct positive ways of viewing being autistic, drawing on counter discourses (Bagatell 2007; Baines 2012).

We need to start by critically examining how previous research has looked at autistic identity. Baines asserts that research on autism tends to focus on how autistic people differ from neurotypical people, but this continues to normalize the discursive construction of autism as something different and "other." She cites Bagatell's assertion that autistic identity is constructed within a social context, and thus to study autistic people's identities, we need to "understand the personal, institutional, and sociocultural storylines that make up their lives" (2012:548). This approach to studying autistic people's identities encourages a focus on the ways autism is constructed by society, and how this can affect individuals. Baines takes the perspective that individuals enact performances through their speech and behaviour that help them negotiate their position in the contexts of school and their social lives (2012). Notably, she remarks that "individuals labelled with autism are often viewed as unable to engage in this collective process" (Baines 2012:548). The existence of this belief about autistic people demonstrates the

importance of research on the ways autistic people negotiate sociocultural context and construct identity.

Previous research finds that autistic people's feelings about autism and the ways they may incorporate autism into their sense of self are contextual (Mogensen and Mason 2015). Baines' contributes to this research, looking at how two high school students were "situated in a larger culture of 'ability', 'success', and 'smartness'," and how they viewed themselves in relation to their social lives with their peers (Baines 2012:548). Mogensen and Mason's findings demonstrate that young autistic people's views about their autism diagnoses are related to the experience they have of receiving the diagnosis, such as at what age they were diagnosed and who told them about their diagnosis. For example, an individual for whom autism was a lifelong identity viewed it positively (Mogensen and Mason 2015).

Another important finding is that identity construction occurs within the context of social relations, as other individuals and communities influence the discursive locations people take up (Bagatell 2007). For example, Parsloe asserts that autistic community is essential to this process, thus showing how the neurodiversity movement is critical to these processes of identity formation and counter-discourse (Parsloe 2015). In a narrative study with students who have a variety of neurodiverse disabilities, including Asperger's Syndrome, Griffin and Pollak find that the concept of neurodiversity is helpful for participants' understanding of diagnosis (2009).

Jones et al., Baines, Bagatell, and Parsloe all look at how discursive location affects identity construction and sense of self. Jones et al. study the use of narratives by autistic adolescents to make sense of autism diagnoses, Baines explores how students represent themselves within different contexts, Bagatell looks at one man's experiences constructing identity, and Parsloe looks at online spaces (Bagatell 2007; Baines 2012; Jones et al. 2015;

Parsloe 2015). Bagatell argues that autistic individuals' identity constructions involve discursive conflicts between identity imposed by the medical model of disability and narratives of identity espoused by autistic activists and the neurodiversity movement (Bagatell 2007).

Baines' findings show that some students viewed being disabled as a bad thing, and distanced themselves from this identity (Baines 2012). Jones et al. assert autistic people experience a paradox of discursive identifications, as they experience stigma around traits constituted as negative while also being aware of positive traits they gain from being autistic (Jones et al. 2015). The effect this paradox has on the autistic community is that many experience both feelings of rejection and identification with their disability, depending on which aspects of autism they see as being part of their identity.

Parsloe's research finds that individuals, who call themselves "aspies," go through processes of reconstituting aspects of autism by reclaiming their identity, which has been pathologized within the dominant discourse. These individuals construct counter narratives of normalcy, symptoms, and agency (Parsloe 2015). In a similar study, participants in Brownlow and O'Dell's research on an online discussion group constructed autism and Asperger's as positive identities, "with a general feeling of rejection to being 'cured' and striving to become NT" (Brownlow and O'Dell 2006:320). Similarly, participants in Bertilsdotter-Rosqvist's study emphasized their Asperger's diagnosis as an identity, instead of a disability, and had various opinions on how much it defined them. However, participants also challenged the idea of autism only being an identity, asserting that people's difficulties needed to be recognized too (Bertilsdotter-Rosqvist 2012).

Bagatell demonstrates that identity construction is a form of agency and the self is a site of discursive conflict (2007). Students in Baines' research wanted to feel agency around how

other people perceived them, with one also expressing the view that he did not care what others thought about him, which was paradoxical as he seemed to both care and not care about others' perceptions. Another student expressed both not wanting to be perceived as acting autistic, but also wanting to "be himself" (Baines 2012:556). As identities are taken up by autistic people, they negotiate the practices of coming out and passing, which are ways individuals embody and perform discursive locations.

### *Coming Out and Passing*

Previous research explores people's experiences of coming out to themselves and negotiating the process of coming out to others, including reasons why people worry about coming out (Bertiltdotter-Rosqvist 2012; Mogensen and Mason 2015). Related to fears about coming out is the concept of passing as non-autistic (Baines 2012; Bertiltdotter-Rosqvist 2012; Mogensen and Mason 2015). Research also examines the way some autistic people see coming out as a form of activism, since it can be a way to disrupt stereotypes (Bertiltdotter-Rosqvist 2012).

Participants in Bertiltdotter-Rosqvist's research saw receiving a diagnosis as the beginning of coming out to oneself, including gaining a new self-understanding, which also involved realizing they were not alone in their differences (2012). After coming out to themselves, they described the experiences of coming out to others about their Asperger's identities. Bertiltdotter-Rosqvist found a shared "ideal of openness" among her participants. However, being open was contingent upon people feeling they could educate others who held stereotypes about autism (Bertiltdotter-Rosqvist 2012:125). This relates to people not wanting to come out because of stigma. Mogensen and Mason describe how "the perceived stigma associated with a diagnosis leads some people to go to great lengths to deliberately mask or



conceal their differences” (Mogensen and Mason 2015:266). In this way fear of stigma makes autistic young people less likely to come out, even when they personally identify as autistic and have positive feelings about this identity. Participants in Bertilsdotter-Rosqvist’s research expressed ambivalence about openness and coming out, because both passing and coming out have benefits and potential harms for autistic people. On the one hand, not being out decreases the risk of discrimination, but also excludes one from getting supports for disability (Bertilsdotter-Rosqvist 2012).

Mogensen and Mason as well as Baines assert that passing is central to autistic and other disabled people’s experiences (Baines 2012; Mogensen and Mason 2015). Mogensen and Mason explain that as these young people try to fit in with their peers and seek to be accepted, they run into issues of whether or not to come out. Mogensen and Mason also explain Thomas’s assertion that navigating choices about disclosure may feel like a form of agency to individuals, but the fear they experience can have long term consequences for their mental health (Thomas 1999 and Goode 2007, as cited in Mogensen and Mason 2015). The two students Baines interviewed both tried to pass through their performances, one to influence perceptions of him from teachers, and the other from students (2012). Participants in Mogensen and Mason’s research described finding ways to cope with impairments, to retain control of their emotions and to be able to negotiate social interactions, in continuous attempts to overcome or minimize perceivable differences (Mogensen and Mason 2015).

Bertilsdotter-Rosqvist describes the disciplinary function of coming out, in regards to both LGBT identity and disability. She describes how when someone comes out as LGBT or as being disabled, they then take on and often perform traits associated with the identity they have taken on. Notably, they do this because they are expected to by society in order for their identity

to be recognized (Bertilsson-Rosqvist 2012). Embodiment is essential to intelligibility, so the label must be performed as well as taken on. In this way, coming out and passing connect back to intelligibility, which connects to discourse, identity, and diagnosis.

Importantly, Bertilsson-Rosqvist found that the coming out process for her participants involved continuous negotiation of cultural notions and expectations around Asperger's. Interestingly, her participants described how they would use their own identities to disrupt stereotypes about autism, by talking openly about their Asperger's (Bertilsson-Rosqvist 2012). This could be viewed as an embodied practice of disrupting dominant discourse. In this way coming out is a discursive act. Although I have discussed these themes individually, the interconnections between them are significant. While the research described here highlights autistic people's identities and perspectives, much more research needs to be conducted with autistic people, as their views are still underrepresented.

### *Gaps in the Research*

Mogensen and Mason assert that "impacts of health professionals' attitudes on children's experiences are rarely discussed in the literature about autism" (2015:266). This gap in the research makes studying autistic people's experiences of treatments and interventions all that more important, especially because we can see that autistic people have had negative experiences in these contexts. They also argue for the importance of research on autistic people's perspectives more broadly, because they can "challenge dominant understandings about young people with a diagnosis of autism" (Mogensen and Mason 2015:267). Post-structural research disrupting dominant discursive constructions of autism has the potential of challenging "policies and practices that continue to marginalise young people with impairments, when diagnosis is

interpreted as defining difference from a norm” (Mogensen and Mason 2015:267). Additionally, significantly less research has been done with autistic people who self-diagnose (Lewis 2016).

The age group I am focusing on is different from much of the previous research, which focuses on teenagers, adults, or wider age groups than I am studying. Looking at the experiences of autistic people in their 20s contributes to previous literature by specifically focusing on people in this transitional stage of their lives. As discussed in the introduction, my reason for interviewing people in this age group is that I am interested in the perspectives of people who have likely been constituted within multiple discourses over their lives, and who can therefore reflect on the experience of being autistic in multiple discursive contexts. Additionally, this age group has been the first to grow up with an understanding of autism as a medical phenomenon, and they were thus more likely to be diagnosed younger with the medical discourse of autism shaping their identities and experiences from an early age. For these reasons, focus on this age group contributes unique perspectives to previous research on autism and identity. My research also adds to the previously mentioned gaps in the literature by focusing on autistic people’s perspectives, including autistic young people with both formal and self-diagnoses, and addressing their feelings around diagnosis and medicalization.

### **Chapter 3: Methods**

In this research, I employed a qualitative exploratory research design. I interviewed four individuals, ages 22, 23, 23, and 26, who identified as having been labelled as autistic at some point in their life, either by themselves through a self-diagnosis or by a medical professional. My goal in this research was to better understand the dominant and counter discourses constituting autism, and how young autistic people themselves embody discursive locations throughout their lives. I also sought to explore what autistic young people think about the multiple discourses constructing autism in our culture. In relation to this, I was interested in the ways autistic individuals negotiate the intelligibility of their identities, in the context of these discourses surrounding autism.

My research followed the similar goal and methodology of Lewis' research on autistic people's experiences with self-diagnosing. Lewis describes asking participants to talk about their experiences and having the researcher try to represent the person's story as they have told it (2016). I believe this kind of methodology is the most respectful of the individuals' experiences and perceptions. However, it is important to note that, while interviews should highlight views and experiences shared by the participant, meaning emerging within interviews is constructed dialogically, between the interviewer and participant.

Researching a small group of individuals echoed previous research by Huws and Jones. They assert that a small sample size is ideal for this type of narrative analysis research, as this is meant to be a detailed study of these particular individuals' views, rather than research that is generalizable to a larger group of autistic people (Huws and Jones 2008). A small sample size allowed me to dedicate more time to an in depth analysis of these individuals' experiences, thus providing insight into the complex, individual views of a group of autistic people. Because of

this small sample size, I was also able to conduct longer interviews, averaging around two hours each, which helped me build rapport with participants.

An important decision I made with recruiting participants was whether to include those with a diagnosis through a medical professional and/or a self-diagnosis. Autistic people and people who study autism have different views on the concept of a self-diagnosis. Huws and Jones describe the process in their research of feeling like they needed to make sure that their participants had a formal autistic diagnosis (Huws and Jones 2008). I believe, as many autistic activists do, that a self-diagnosis is valid and is the only accessible option for many individuals. In my literature review I discussed reasons why some people have a self-diagnosis, but are unable or do not wish to get a formal diagnosis.

Baines describes how, although a formal diagnosis was required for participation in her study, she made the decision to analyse how labels impacted the experiences of the individuals in her study, rather than focusing on diagnosis in terms of validity. By taking this research approach that prioritized the sociocultural experiences connected to a label, she found that “the nature of a label itself” was actually less significant than the ways students negotiated their academic and personal lives (Baines 2012:548). Brownlow and O’Dell go further in challenging the idea of formal diagnosis as necessary for research, bringing in a post-structural critique of the medical narrative. They assert that “in the current research our aim was to document some of the challenges to the construction of autism and the diagnostic processes and the power given to ‘experts’ in the field” (Brownlow and O’Dell 2006:320). To bring this perspective into their research they deliberately chose to focus on how individuals identified, rather than whether they had a formal diagnosis (Brownlow and O’Dell 2006). My goal was to highlight autistic people’s perspectives, including their views around how autism is constructed and diagnosed. Therefore, I

thought it was crucial to prioritize how participants identify over how they are labelled within medical discourse.

The general issues and topics guiding my research questions were: life experiences with autism identity and/or diagnosis; views and definitions of autism and neurodiversity; identity construction and embodiment; perceptions of conformity, non-conformity, and difference; feeling understood/misunderstood (as a method for exploring intelligibility); and social and temporal context. I determined these issues by identifying themes in the previous literature and they guided the construction of my interview questions, but these issues were broad going into the interviews and were not intended to limit what participants would talk about. Some themes that emerged through coding reflected the interview questions and some did not.

In developing my interview script, I chose a semi-structured approach with questions to facilitate the emergence of narratives through the interviews (see Appendix A for my interview script). As my goal with this research was to prioritize participant perspectives, I wanted an interview style that would let participants share what they felt was important, while also making sure all of my issues and questions were covered. I employed approaches to conducting narrative interviews outlined by Smith-Chandler and Swart, who discuss methodologies for narrative research with disabled people. They suggest conducting open-ended interviews that focus on participant experience and stories (Smith-Chandler and Swart 2014).

## SAMPLING

I employed snowball sampling through two Facebook groups that had a lot of members identifying as autistic: “Intersecting Sexualities, Gender Identities and Neurodivergence” and “Neurodivergent Aesthetics.” These groups were created by and for neurodiverse individuals with different disabilities, many of whom identify as autistic. I posted my invitation script in my

Facebook account as well as in these Facebook groups, and asked people to share the invitation widely. My decision to recruit participants through Facebook groups for autistic and neurodiverse people was based on research showing the significance of the internet as a space of communication and socializing for autistic people, both formally and self-diagnosed (Brownlow and O'Dell 2006). It is apparent that many autistic people are using Facebook, and the internet in general, to build relationships and communicate with each other. This use of the internet is significant when thinking about how autistic people negotiate discursive locations and seek to be understood. A Facebook group allows people who may struggle with communicating and socializing outside of the internet to talk with like-minded people, share advice, and make friends (Brownlow and O'Dell 2006).

In the invitation script, I asked people to respond to the invitation by emailing me, without liking, commenting on, or sharing the post. I asked them to avoid interacting with the post on Facebook to give them more anonymity surrounding their participation. In the research invitation, I said that participants would need to have been labelled or identified as autistic, either through formal or self-diagnosis. Participants needed to be able to provide detailed descriptions of their experiences. Participants also needed to be able to attend the interview independently. For participating I offered individuals a ten dollar gift card to Tim Hortons or another coffee shop, as three out of four of them were not in Canada.

I told participants that they would be asked about five themes or topics, and these were listed in the research invitation as: ideas about autism and neurodiversity; views about conformity and non-conformity; experiences of forming identities; feelings of being understood or misunderstood; and changes in experiences, at different times and around different people.

This list was meant to be a summary of the issues guiding the research questions so that people would have a sense of what the research would be about and what they would be asked.

There were opportunities during the interviews for participants to share additional views. They were given several options for interview methods and locations to accommodate their needs, following previous research on disability and autism. For example, Jones et al. note that conducting online interviews may be more accessible to some autistic individuals who may experience limitations in speaking and social interactions (2015). Smith-Chandler and Sward similarly note that participants should be allowed to choose how they wish to generate data, to fit how they are able to and prefer to express themselves (2014).

## DATA COLLECTION

When people emailed me about participating I sent them an email with information about my research, including the purpose, the kinds of questions they would be asked, the expected length of interviews, compensation for participating, and information about confidentiality, including that they would have a pseudonym. I let them know that the interviews would be audio recorded and transcribed, and that they would be able to edit their interview transcripts. I also explained the consent process, including telling them they could decline to answer any question and withdraw from the study at any time without any penalty or loss of compensation. In this first email I also asked them for their availability to schedule a time for the interview and asked whether they would prefer an interview over email or Skype. After I heard back from them we set a time for the interview.

All four of my participants chose to conduct their interviews over Skype, with one person choosing to use only audio with no video. Another interview started with video, but changed to just audio because of problems with the internet connection. By providing different options for



interviews to participants and letting them choose the format of interview most comfortable to them, I was able to create a more accommodating and welcoming space for participants. As part of this concern for creating an accommodating environment for participants, I stated that sensory items would be allowed during the interview. These items, which include small fidget toys that can be anything that is helpful for the individual, are tools people can use to help focus and calm themselves. For in-person interviews, of which I did not have any, I offered to bring fidget toys, music, and ear plugs. All these things would help in creating a comfortable space for participants.

I asked participants to print out the consent form before the interview. At the beginning of the interview I reviewed the consent form with them, asked if they had any questions, and asked them to sign it then. I asked them to send me a pdf or picture of the signed consent form after the interview. Then I talked with participants about my reasons for conducting this research, to give them context and build rapport. I did my best to not share my own ideas during the interviews themselves, but at the end some of the participants asked me questions about my own thoughts around autism. My connection to my research is being a neurodiversity activist. I started a community group around disability, mental health, and neurodiversity towards the end of my Master's program. I have been organizing events for this group on my university campus. I started becoming involved in neurodiversity and disability activism about three years ago when I was doing an internship in disability rights. This positioning in relation to my research helped establish trust and rapport with participants.

Throughout the interviews I gave positive and affirming feedback, while trying to maintain neutrality and not influence their answers, although this is unavoidable in interviews to some extent. This was important because they were sharing intimate details of their lives and

experiences that were emotional and sometimes upsetting. I also included time for chatting about interests, as autistic people often have specific, unique interests that are an integral part of autistic identity and culture. These interests were very diverse, including “Doctor Who,” Lady Gaga, Bjork, Japan, Iceland, comic books, and the history of autism. Having time to chat about interests seemed to help participants feel more comfortable and built rapport.

Interviews were expected to take around 1 hour and 30 minutes. The first interview ended up taking 2 hours and twenty minutes. After 1 hour and 30 minutes I asked the participant if she wanted to continue with the interview at that time and she said yes, so we continued the interview until we finished the questions. Another interview took 2 hours and 30 minutes, mostly because we had trouble with the internet connection and the Skype call was cut off several times. I asked the same question of that participant and he also wanted to continue the interview. The other two interviews both were around 1 hour and 20 minutes each.

In previous research with autistic people, such as that of Mogensen and Mason, the style of the interviews was planned around communication styles of autistic people. Mogensen and Mason, for example, changed open ended questions to more structured ones based on how each participant communicated in the interview (2015). I noticed during my interviews that sometimes my questions were phrased in ways that could be confusing, and I could have put more thought into how someone with a different communication style might respond to the questions. For instance, I had questions about being understood, which I meant to be about intelligibility and acceptance by others. However, these were sometimes perceived as being about whether a participant was literally understood in conversations and interactions, which was still interesting.

I recorded the interviews through audio recorder programs both on my phone and on my laptop, in case one recording did not work. I transcribed the four interviews using the

transcription software, InqScribe. I chose to include incomplete sentences and filler words, such as “like” in the transcriptions, because I felt this would show the amount of time it took participants to answer the question and could potentially show how much comfort and clarity they had around answering each question. I did not include incomplete words. I typed “inaudible” for anything I could not understand in the interviews, and put anything I was not sure about in quotes with question marks at the end like this: “??”. After I transcribed the interviews once, I went back and re-listened to all of them to increase the accuracy of the transcriptions. Interview transcripts ended up being an average of 25 pages long, single spaced.

After transcribing the interviews, I employed member checking for trustworthiness and anti-oppressive goals, as I wanted to make sure participants’ ideas and opinions were represented as they wanted them to be. I agree with Smith-Chandler and Sward that participant voices should be central to the research. Member checking is central to their methodology, as they assert that narratives should be shown to participants so they can ensure the content reflects their perspective accurately. Their goal with narrative research is emancipatory, in that they see documenting people’s personal experience of identity as a way to counter stereotypes and highlight a diversity of experiences (Smith-Chandler and Sward 2014).

Before emailing participants their interview transcripts for member checking, I highlighted the inaudible and unclear portions of interviews in green and blue to make them easier for participants to find. I asked participants to let me know if the unclear portions were correct and to fill in the inaudible portions as they were able to. Because I had so much data, it was ok for words and sentences here and there to be inaudible. I found while transcribing interviews that at these places participants were often thinking out loud while in the process of answering questions, so inaudible phrases were often repeated.

I also looked through the transcripts and deleted anything that could identify the participants, such as names of towns or cities they were from and university names. I also wrote comments to check in about whether I should leave in or remove particular information. For example, one participant was involved in activism around autism and mentioned particular issues she talked about when blogging and at a conference, so I checked in with her about whether I should be vague about the particular issues she was involved in, since that is public information. I chose a pseudonym for each participant and wrote each person's pseudonym at the top of their transcript for member checking, giving them the option of changing it and choosing their own.

In my emails to participants for member-checking, I asked them to add or delete anything they wanted and to use track changes, so I could see what to remove from their transcripts. I also emailed with some of the participants again to clarify some information. When I received the transcripts back from participants, I accepted all the changes, so that I would have a completed transcript ready for coding. I had intended to interview four to eight individuals, and with the four interviews I reached saturation of data so I decided I did not need to interview more people.

## DATA ANALYSIS

I conducted coding using thematic analysis, drawing from Ezzy (2002) as well as Savin-Baden and Howell Major (2013). Thematic analysis involves taking time to become familiar with the entire texts and then while coding “the researcher can rely on intuition and sensing, rather than being bound by hard and fast rules of analysis” (Savin-Baden and Howell Major 2013:440). Savin-Baden and Howell Major assert that it is among the most useful forms of data analysis. Ezzy also argues for the benefits of the use of intuition in this coding methodology (2002). I chose to employ this method of data analysis because the semi-structured nature of the interview format necessitated less rigid categorization and interpretation. Through the data

collection and analysis, I familiarized myself with the data and the way I approached analysis enabled me to better understand my participants in a holistic way, acknowledging their views within the context of the interview as a whole. Savin-Baden and Howell Major explain one can develop insights about the data “through the process of immersion in data and considering connections and interconnections between codes, concepts and themes” (Savin-Baden and Howell Major 2013:440). Since themes emerge organically from the data, thematic analysis is an inductive process. Ezzy explains “while the general issues that are of interest are determined prior to the analysis, the specific nature of the categories and themes to be explored are not predetermined” (2002:88). There were general issues and topics related to previous literature that the interview questions were developed to explore, and they changed slightly during coding, such as subthemes emerging for *Intelligibility*, and themes emerging that differed from previous research.

Following the thematic analysis methodology from Savin-Baden and Howell Major (2013) and Ezzy (2002), I first read through all the interviews, which I had already become familiar with through transcribing. I then set about coding each interview. I read through the interviews writing comments in the Word documents, being as thorough as possible in noting all meanings I observed in the narratives. If I did not think a section had significant meaning, such as a participant talking about their favourite television show or musician, I coded that as such, but still commented on what they liked about the show or person, as I thought that could be significant. While taking notes on my computer, I took broader notes on topics and emerging themes by hand in a notebook, as this helped me reflect on and analyse the data. I also categorized my notes by writing associated themes next to them on my computer. As I coded all the interviews, I took notes about when I saw reoccurring themes, drawing connections between

participants' narratives. I took notes on the emerging themes: *Diagnosis; Intelligibility*, the most significant theme that had many subthemes; *Terminology; Medicalization; Identity; Life Course*; and *Internalizing Responsibility*.

## PARTICIPANT INTRODUCTIONS

Before starting the results section, I will briefly introduce each of the participants to give a sense of who they are and the context shaping their narratives. Participants live in four different countries in North America and Europe, none of them living near me. Because of this, I conducted all interviews over Skype, with two of them being just audio. Participants told me they enjoyed being part of the research and having the opportunity to talk about these questions and issues. Two of the participants are LGBTQ and I address that in their introductions because of intersections between their LGBTQ identities and autism.

*Sarah*<sup>1</sup> (age 22) is a Master's student in London studying human rights law. She has known she is autistic from a young age, largely because she was diagnosed then in some way, specifically with Asperger's, but is not formally considered autistic because she does not have the paperwork. She is currently still seeking a formal diagnosis. She presented on a panel at a conference for autistic women and girls, and also contributes to a blog with other autistic young people.

*Mikkel* (age 23) lives in Denmark and is in college. He grew up in special education, at a school specifically for autistic people, and has had an autism diagnosis, Asperger's specifically, from a young age, finding out when he was seven from a teacher. He is transgender and has been involved in transgender rights activism in Denmark. He also has dyscalculia and is seeking a diagnosis for that.

*Grace* (age 23) has lived in both the United States and Canada, currently living in Canada. She studied history for her undergraduate degree and her work is in welding and writing. She identifies as bisexual and talks about being autistic as a bisexual woman. She was diagnosed in high school at age 16 with Asperger's, originally being misdiagnosed with a learning disability.

Lastly, *Rachel* (age 26), who lives in the United States, went to school for her undergraduate degree at a small college, where she thinks there were a lot of students with neurodiverse identities and diagnoses. She then went to school for library science, but had to leave that graduate program because she struggled with her mental health. She has bipolar disorder and has dealt with that since she was a child. At the time of the interview, she was taking time off from working due to bipolar and was planning what to do with her life next. *Rachel* self-identifies as having Asperger's, having realized that three years ago.

*Rachel* and *Grace* both have an autistic parent, *Rachel's* father and *Grace's* mother, though *Rachel's* father passed away four years ago before she realized she was autistic too. Each person's experience of identifying and dealing with the diagnostic process is particularly significant for this research and will be explained in more detail shortly.

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<sup>1</sup> Pseudonyms are used in place of participants' names to increase anonymity.

## Chapter 4: Results

As explained in the methods chapter, some of the following themes that emerged are related to previous literature and were central to my research questions, including: *Diagnosis*, *Intelligibility*, *Terminology*, and *Medicalization*. These themes changed during data analysis, especially *Intelligibility*, for which numerous subthemes emerged.

The themes of *Intelligibility* and *Terminology* had subthemes, which I will briefly outline. *Intelligibility* is a particularly rich theme, as it includes all the ways that my participants feel understood and misunderstood, as well as the ways they seek to gain understanding from their peers and society more broadly. The theme of *Terminology* looks at the language used by participants and people in their lives. This importantly includes discussing the terminology representing the counter discourse of neurodiversity, which is central to autistic activism. The themes of *Intelligibility* and *Terminology* especially illustrate the complex ways these individuals negotiate their identity and expression within discursive contexts in order to make themselves understood. We can also see how significantly discourse shapes their experiences and the impact of intelligibility in their lives. The theme of *Medicalization* looks at participants' experiences in medical contexts as well as with therapists. This theme also looks at ways in which their subjectivities have been medicalized, such as in educational institutions. *Diagnosis* involves participants' experiences receiving and seeking formal diagnoses as well as experiences self-diagnosing. This theme also explores participants' perspectives about diagnoses and diagnostic processes.

New themes that emerged during coding, and were not related to the research questions and previous literature, include: *Identity*, *Life Course*, and *Internalizing Responsibility*. *Life Course* includes subthemes of worry about social pressures and expectations for the future, as well as changes throughout participants' lives around feeling understood and their feelings about



being autistic. This subtheme is particularly interesting, showing significant changes in how these participants have conceptualized their autistic diagnoses and identities over their lives.

The last themes in this discussion will be *Identity* and *Internalizing Responsibility*.

*Internalizing Responsibility* is an important theme as it highlights impacts of internalized ableism. Discussion of each theme and subtheme will include quotes from participants as well as analysis of their views and experiences. All of the themes and subthemes are outlined in the chart below:

| Themes                       | Subthemes   |
|------------------------------|---|
| Diagnosis                    |   |
| Intelligibility              | Feeling Misunderstood<br>Disbelief and Faking<br>Misunderstanding Autism<br>Mental Health Impact of Unintelligibility<br>Feeling Understood<br>Making Oneself Intelligible<br>Diagnosis for Intelligibility to Oneself<br>Expanding Intelligibility<br>Community<br>Language to Talk about Oppression |
| Terminology                  | Language and Context<br>Neurodiversity  |
| Medicalization               |   |
| Identity                     |   |
| Life Course                  | Changes in Feeling Understood<br>Changes in Feelings about Being Autistic<br>Hopes and Fears for the Future   |
| Internalizing Responsibility |   |

## DIAGNOSIS

*Diagnosis* is a good theme to start with, as it is at the centre of discourses around autism, and affects autistic people's intelligibility. The experience of receiving the diagnosis and how people identify with their diagnosis is a significant part of autistic people's lives. As illustrated in

the participant introductions, they have had varied experiences in when they received a diagnosis and the kind of diagnosis, including formally diagnosed, self-diagnosed, and in-between as in *Sarah's* case, because she was labelled as autistic but has no documentation. She talks about how autistic people are told they need documentation with a diagnosis, and her narrative demonstrates a long, complicated process to acquiring this, though university disability offices can help. She tried to get a formal diagnosis before in her undergraduate degree, but the process took a long time so she graduated and moved before she was able to be assessed. She expresses the anxiety she had around documentation:

*I was asked to see, when I got here, the disability service advisor here. And I put off making an appointment. Put it off and put it off, because I didn't know what to say to her because I knew that I would have to go and say, you know, "I know I disclosed, but I don't really have the paperwork."*

Fortunately, she had a positive experience with her appointment and was referred for an assessment. It is clear from this story that, while the process for assessment itself can sometimes be difficult, the anxiety *Sarah* had about talking to professionals was also a barrier. In the assessment and diagnostic process sometimes individuals are misdiagnosed, like *Grace*, who was first diagnosed with a learning disability that was later changed to Asperger's.

Participants also talk about the connection between a self-diagnosis and a formal diagnosis. Even though *Sarah* strongly identifies as autistic, she expresses anxiety that she might go to get the assessment and end up being told that she is not autistic by the medical professional:

*I'm hoping it will be quite straightforward. Because at this point I'm essentially, pardon the phrase, trying to find out if water is wet, you know. I'm trying to find*

*out. You know. And it is something that worries me, that they will turn around and say "actually you're not," because then what, you know, then what?*

In terms of intelligibility, this experience would be disrupting for both *Rachel* and *Sarah*, because the autistic identity has helped them to understand themselves and their lives. For example, when *Sarah* was bullied in secondary school knowing she was autistic helped her not internalize negative feelings about herself, because she had a label to explain her differences. Both *Sarah* and *Rachel* worry about losing this identity. The intelligibility gained from identifying or being diagnosed as autistic will be explained more within the *Intelligibility* theme.

*Rachel's* situation is similar, though hers is different because she has never had an assessment of any kind. She is currently self-diagnosed and is considering getting a formal assessment. She is undecided about whether to get an assessment because she's afraid she'll be told she's not autistic. *Rachel* says she likes the idea of being autistic, because this label and identity provides an explanation for the ways she is different. Without this label she says she would feel "weird," and that feeling of difference without explanation would negatively affect her self-esteem. She feels like she would lose this if she gave up the identity. This aspect of *Rachel* and *Sarah's* narratives is also connected to the forthcoming themes of *Intelligibility* and *Identity*.

*Rachel* considers what she would do if she was not diagnosed, saying she would either have to tell herself that the doctor was wrong, which goes against dominant medical discourses, or she would have to give up the identity, which would negatively affect her self-understanding. However, as mentioned, a diagnosis is helpful in gaining intelligibility and for this reason *Rachel* feels it would be validating to get the formal diagnosis, particularly because people would have

to believe her identity as autistic, which they often do not. She asks herself questions that illustrate the complexity around diagnoses and identity:

*If I did the formal diagnosis thing, it could either be awesome or horrible. And I'm like, is it worth the risk? Is it worth the risk? Is the joy of validation worth the risk of like being told that I'm not autistic? And then either having to like continue to tell myself I'm autistic and just say the doctors don't know what they're talking about, or like having to give up that identity.*

Part of this tension between having a self-diagnosis and seeking a formal diagnosis, which the individual may or may not get, has to do with the place of medical knowledge in society. The idea *Sarah* and *Rachel* are considering is who has the expertise to give a diagnosis and whether the testing instruments, such as the diagnostic criteria, for an autism diagnosis can be questioned. We can already see *Rachel* questioning medical knowledge as dominant when she suggests that a doctor could be wrong and that she may decide not to listen and continue identifying. She also made comments about “at the very least” having some of the same traits. Even without a diagnosis, she is able to use autistic diagnostic criteria to make sense of her identity and experiences.

Within this theme, participants are negotiating various autistic subject positions. On the one hand, they identify as autistic and see this as a central aspect of their identities, and notably as something positive. However, dominant discourse constitutes being diagnosed with autism as the dominant autistic subjectivity. This means that these participants feel they must be diagnosed in order to identify. This tension between the autism as identity and autism as diagnosed subject positions will need to be explored in future research due to space limitations, but I will address it briefly under the theme of *Identity*. As I mentioned, questioning of medical knowledge as having

the most validity is also part of this theme, especially as *Grace* explains that she was misdiagnosed at first. It is interesting to note that *Grace* finally received her Asperger's diagnosis because her mother, who learned that she was also autistic, believed the first diagnosis was wrong. The story of her mother, who is not a medical professional, being part of the diagnostic process is interesting, as this also questions the dominance of medical knowledges. At the root of worry about self-diagnosing and not being able to get a formal diagnosis is the fear that people will think these individuals are "faking" their diagnosis. Though "faking" is relevant for this theme, it has more to do with people's identities being understood and accepted so I will discuss it in more depth for the *Intelligibility* theme.

## INTELLIGIBILITY

This theme has numerous subthemes, as intelligibility and unintelligibility can be experienced in many different ways and various contexts of one's life. The subthemes are *Feeling Misunderstood, Disbelief and Faking, Misunderstanding Autism, Mental Health Impact of Unintelligibility, Feeling Understood, Making Oneself Intelligible, Diagnosis for Intelligibility to Oneself, Expanding Intelligibility, Community, and Language to Talk about Oppression*. These subthemes connect to the other themes that emerged, such as diagnosis providing intelligibility, people feeling intelligible in their identities, and how dominant and counter discourses shape intelligibility. I have structured my discussion of this theme to move from ways people feel misunderstood and unintelligible, to experiences of feeling intelligible, and then on to what makes people intelligible and how they find agency in making themselves intelligible.

### *Feeling Misunderstood*

Participants express feeling frequently misunderstood. *Rachel* says people misunderstand her all the time. She doesn't behave the way they expect her to and they don't understand. She explains:

*People misunderstand me all the fucking time. It's horrible. I always feel like. I always feel like my intentions are never understood by other people. And it's really hard for me. It's like, I just, like. I upset people without meaning to, and they like refuse to realize that like I didn't do it on purpose.*

Similarly, *Grace* says most people don't understand why she does things. *Mikkel* says people respond to him being autistic in mixed ways. He deals with stereotypes, negative comments around people not believing him, people making comments about hierarchies and functioning labels, and other "weird" comments coming from people not knowing about autism. Additionally, he describes feeling outside of the transgender community because he is also autistic, and has been discouraged from mentioning his autism in conversations about transgender rights because of stigma around autism. This points to issues around intersectionality, how significantly autistic identity is stigmatized, and demonstrates issues of ableism even in otherwise progressive communities.

Another aspect of misunderstanding participants express is feeling that society as a whole doesn't understand them and isn't going to. *Grace* says neurotypicals just are not going to understand how autistic people communicate:

*I wish this wasn't the case, but it is unfortunately the case, that way too many people don't understand autistic body language. And they're never going to learn.....And the not going to part is unfair, but it's the truth. They're not going to.*

Similarly, *Mikkel* talks about how he felt angry at society for how he's been treated, saying:

*It's just sad if this society cannot accept me.*

This outlook conveys a sense of hopelessness about gaining understanding that illustrates how deeply misunderstood these individuals feel.

The narratives within this theme demonstrate how unintelligibility can be experienced both at an inter-personal level as well as a societal one. These participants express that in their daily interactions they feel misunderstood by people and they express feeling misunderstood by society in general. On the one hand, this feeling of being misunderstood by society could come from repeatedly feeling misunderstood in their interactions and, as I mentioned, feeling hopeless about possibilities of gaining understanding. On the other hand, this belief that neurotypical people will never learn autistic body language or that society cannot accept and understand autistic people may come from involvement in autistic communities and activism where individuals learn about others' experiences and social issues affecting this community.

### *Disbelief and Faking*

One of the most significant ways autistic people are misunderstood and unintelligible is when people do not believe them about their autistic identities, an experience many share. Even though three out of the four participants had some kind of formal diagnosis, they all experienced disbelief on some level with the majority being accused by others of "faking" their autism. *Sarah* worries that people won't believe her when she tells them she's autistic. It is interesting that she worries about this, while also saying she has been able to avoid it. This might be a frequent enough occurrence for others in the community that *Sarah* has apprehension about it, even if it has never happened to her in particular:

*Sarah: I do worry about kind of getting lots of awkward questions and like "oh, but, if then how can you be here? How can you do this?" And, you know. I guess, accusations of faking. Which, I've been lucky enough, I've been lucky to avoid. But I do still worry about that side of things.*

In contrast, *Mikkel* has experienced being doubted by others:

*Mikkel: And then when I changed schools into a school where not everyone was autistic, then I got a lot of questions for me being autistic. And lot of those "no, you can't be autistic because" or "Oh, I don't think you have autism" and all these comments.*

*Rachel* shares that people don't take her seriously when she talks about being on the autism spectrum, expressing dismissal and disbelief. Only a few people believe her, while the rest dismiss her identity. Interestingly, some of these people agree that she has traits associated with Asperger's, but still don't agree with her self-diagnosis:

*People who are like "oh, well. I don't really think you have Asperger's, but I understand why you think that. Like, you are really weird, but I don't think you have Asperger's." So they're like, they're like admitting that I have these odd traits, but are like "no, you don't have Asperger's" for some reason.*

This response is interesting, because it demonstrates complexity in how people perceive autism and identity. They may recognize that someone has autistic traits, here labeling them as someone being "weird." Their description of autistic traits as "weird" highlights the extent to which behaviours associated with autism are viewed as non-normative. While people recognized that *Rachel* had these traits, they were reluctant to agree that *Rachel* could get a diagnosis or identify with autism, perhaps because of the stigma around autism. In a similar way, while *Grace* says



people do recognize she has autistic traits and behaviour, they act surprised to learn she's autistic:

*But the people I meet, who aren't intimately familiar with me or I just know their face. 'Oh I never would have guessed!' is the response I've gotten. I think 9 times out of 10, which I'm getting kind of tired of, to be honest.*

Rachel shares why it is so hurtful to be dismissed and accused of faking, expressing that identifying as autistic makes her feel intelligible, but other people can take that away by dismissing her:

*Then it's like "well I have a valid reason to be this way and I can be this way now." So I was really excited. I was really. But then like I talked to a couple people about it and they were like "Sam, you don't have Asperger's. What are you talking about?" So then I had to be like "oh, ok. Maybe I'm just weird."*

This quote connects to the issue of identity I am addressing throughout this thesis, where having this identity provides an explanation for difference, which helps these individuals accept themselves. Being disbelieved can thus have a negative impact on their self-esteem. Fortunately all the participants have people in their lives who validate their identities.

As I mentioned, a lot of disbelief in people's diagnoses comes from stereotypes and assumptions about what autistic people are like. Some neurotypical people assume that someone must not be autistic if they do not act the way they expect. What is also interesting is that participants say they are disbelieved because their traits do not seem "disabling" enough. Sarah and Mikkel both share that people do not believe them because they are going to school, which some people assume autistic people cannot do. Grace and Rachel describe being disbelieved because their personality traits are recognized as different, but somehow not different enough for

them to be autistic. These misconceptions from some non-autistic people may come from misunderstanding around autism being a spectrum, as there is actually great diversity among autistic people. Stigma that comes from misunderstanding autism is also a significant factor in disbelief and accusations of faking. Lack of understanding about autism itself affects whether or not these individuals are understood by people they interact with and in society more broadly.

### *Misunderstanding Autism*

Aside from having their own identities questioned and doubted, participants often find themselves unintelligible when talking about autism because of a lack of understanding of what autism is and what terminology means. *Rachel* doesn't like to talk about having Asperger's to people, because she feels they won't understand her. Similarly, *Mikkel* describes having to ask himself if he'll be safe and understood if he describes himself as autistic:

*Sometimes I have been in some groups and then instead....I usually just say "I have a disability. Therefore I worry about my future blah blah blah." To explain that because I'm not sure what kind of people will read my comment. And I know that maybe I could, I could experience like some person who was like "oh yeah, I know someone with autism and therefore blah blah blah." And I'm not interested in like having these stereotypes on me.*

He knows that people have stereotypes about autism and might not understand, so he would rather just not talk about being autistic to avoid that. This quote and the narratives in the previous subtheme illustrate how stereotypes are a significant part of how autistic people are misunderstood. *Mikkel* has also felt misunderstood by teachers and professionals, such as a therapist he saw about getting hormone treatment to medically transition. He has had professionals who said things demonstrating that they do not really understand autism. When he

left his special education schooling to go to college, he was surprised at how much he had to explain autism to people, especially teachers, and at all the questions he received about being autistic. At this point, he realized how unintelligible he was, as he had gotten used to being autistic and had come to expect people would understand. His surprise about professionals and teachers not knowing about autism suggests an expectation from him that those who work with young people and disabled people should have an understanding of autism, while young people not knowing might be more understandable. Also, it is significant that he has experienced medical professionals, in particular, not understanding autism, as this demonstrates unintelligibility of even a medical autistic subject position.

Interestingly, *Grace* adds that most people don't have a good understanding of what autism is, including most autistic people, which is an intriguing perspective and rings true in many ways because autism is such a complex identity and experience

*And just a lot of people don't have a good understanding of autism. They get.*

*Most autistic people don't have a good understanding of what autism is.*

*Whenever I ask, like you know, somebody "what's the deal?" the answer I get is "we're not quite sure."*

This quote connects to *Mikkel's* experience of medical professionals lacking knowledge about autism in an interesting way, because, according to *Grace*, even autistic people do not really understand autism. More directly around being understood when talking to people about autism, she says the experience of being autistic itself may be difficult for people to understand:

*I think that sounds kind of weird, learning body language. Because it's supposed to be so innate. Like, for me, it's not.*

This highlights how autistic people's experiences can be unintelligible because they are so outside of what non-autistic people may be familiar with. Body language is *supposed to be so innate*, so *Grace* believes talking about learning it sounds weird. Autism is misunderstood in society to the extent that participants feel that they cannot talk about their experiences without being seen as *weird*.

The previous three subthemes demonstrate various ways that autistic people can experience unintelligibility, being misunderstood generally, being disbelieved, and realizing that autism itself is not understood in society, which ultimately affects whether they are understood. The next subtheme explores the impact feeling misunderstood in these different ways has on these individuals.

#### *Mental Health Impact of Unintelligibility*

Not feeling understood by people around you as well as society as whole has implications for emotional well-being. I asked participants to share what it feels like when they are misunderstood. *Rachel* says she feels frustrated when people are dismissive of her identity. When her intentions are misunderstood and she experiences conflict with friends, she describes the feeling as horrible and painful, wearing on her and making her not want to get out of bed, even feeling similar to depression:

*The day after it happens, some kind of rejection like that happens, or someone misunderstanding, I get really down. It's depressing. I mean, it feels like depression. It's hard.*

Similarly, *Mikkel* describes feeling angry and frustrated at everyone as well as himself, so his feelings of anger are also self-directed:

*So I get like very angry at them and myself and like everyone, and everything in the world.*

The pity-centred discourse around autism that he grew up with affected his self-esteem, as he internalized it and learned to view himself and his autism negatively:

*"It's so sad you have autism" thing. That's usually like the first thing I heard when I was diagnosed, basically. And it was like, you know it's....And I said, these kind of negative thoughts stuck with me a lot of time in my life, and it's still like there sometimes.*

Grace says being misunderstood is unnerving and causes her a lot of anxiety. She frequently worries that people will even hate her because of her autistic traits, expressing her distress when she says:

*'I really hope you don't hate me for that.' I've had that thought constantly.*

She also feels drained a lot because of the amount of energy she needs to put in to explaining herself to people. Sarah says being misunderstood feels frustrating and horrible for her. She internalizes her feelings when this happens:

*I'm trying to get better at this, but sometimes I will just internalize it. And that's bad. That has some. That has some. That can sometimes make me feel really anxious and generally have some pretty negative outcomes.*

These quotes show how participants feel shame and responsibility for being misunderstood, an issue I will address in the theme *Internalizing Responsibility*. They internalize misunderstanding, which makes them feel guilty, angry, anxious, and depressed. This is an important finding, because as mentioned in my literature review, autistic people often have comorbid mental illnesses (Lewis 2016). In these quotes my participants share one significant

source of distress for them. While feeling misunderstood has negative impacts, participants also described how good they feel when they are actually understood. *Grace* says being understood makes her feel so happy and affirmed:

*It's just really nice when someone. It's so rare to click and just to see actually someone click. It's good.*

*Rachel* says being understood means being able to relax and not having to worry about having a *good façade*. It means she can stop worrying so much about how people see her. *Sarah* describes feeling understood as being able to let her guard down and feeling like she is in a *safe space*. *Mikkel* says that his mental health has improved now that he accepts himself more, a big change from how he felt when he was younger. The participants express that feeling more understood now has improved their mental health by validating them and lessening their worries. While my participants describe aspects of their experiences that cause distress, here they share what can help improve their mental health.

### *Feeling Understood*

My participants also talk about feeling understood, specifically who understands them and identifying what people can do to understand. *Rachel* says her mom truly understands her and accepts her when she struggles with bipolar disorder in ways that affect her behaviour. She also has a core group of friends, who have stood by her and made an effort to understand her. *Grace* says her family and friends understand her, explaining that even though it's hard to communicate with people and she often feels unintelligible, she has some friends who are caring enough and who are understanding. *Sarah* and *Mikkel* both have had experiences of finding communities in which they felt understood, *Sarah* in the "Doctor Who" Society at her university,

and *Mikkel* with his trans and autistic friends, who understand both of his central identities, being trans and autistic:

*Mikkel: I have like a few friends who both are trans and autistic, and when I meet them I'm like so happy, because then I feel like they can like understand both of me. I don't have to worry.*

*Sarah: I got to know people over a long period of time. And they understood me.*

*Who Soc was somewhere where that process happened quite quickly.... So these were people who would see me kind of start going a bit haywire. Who would see me shut down. Who would have to calm me down from screaming. You know.*

*And, on the one hand, that can be quite embarrassing. But, on the other, it meant that they got it, so if it happened again it wouldn't matter.*

All the participants share that, even though they often feel misunderstood, they do have people in their lives who understand them, and this understanding has to do with both their identities and traits of their disabilities. *Rachel* says understanding is something people have to put work into. *Grace* says people understanding is connected to knowing her well and *Rachel* says it's connected to them trusting her, which is significant because so much of her experience of misunderstanding is around people assuming she intends to hurt and offend people. It means a lot to *Rachel* when people really try to understand her, as it shows they care and are a good friend to her. *Rachel*, *Mikkel*, and *Grace* explain what people need to do to understand them:

*Rachel: I have a core group of people who seem to really. Even if they don't get me, they're willing to listen to me when I try to explain.*

*Mikkel: But they're willing to like listen to what's being said. And not just the diagnosis, but be like "oh, ok. You said that you had problems in school because people didn't understand you."*

*Grace: I need for them to be open and willing to basically sit down and have me take at the very least 10 minutes, sometimes half an hour of their time to explain to them this is how it is. Because it's a complex thing to explain.*

It is notable that these three participants' ideas of what it takes to understand them centre around listening, because being given the space to share their perspectives provides agency. This demonstrates that intelligibility involves other people understanding, but also has to do with being given the means to shape the way one wants to be seen and understood. The significance of agency for feeling understood brings us to the next subtheme.

### *Making Oneself Intelligible*

The remaining discussion of the theme of *Intelligibility* will look at the ways participants take their intelligibility into their own hands to make themselves understood and to expand intelligibility for the autistic community as a whole. Related to these two subthemes are having the language to talk about one's oppression as well as autistic community.

*Rachel* uses coming out, or disclosure, as a strategy to avoid miscommunication and get people to understand her, saying that when she becomes friends with someone she will soon tell them that she has Asperger's, and tell them how she needs to communicate, such as being told things directly. She also generally loves talking about autism and her experiences, which could be a way she validates her own experience. *Mikkel* says seeking understanding means he has to be more open with people, which also makes him vulnerable:



*So, like I feel, for me it feels worse, but I also feel that it's just how I feel it because I'm more open about it. And then therefore more vulnerable. But I also had positive feelings because I had more of my friends coming to me actually and be like "hey. I heard you're autistic. I just got a diagnosis. Can we talk?"*

This demonstrates complexity in attempting to make oneself intelligible. There are positive outcomes, but people often take risks by seeking understanding through openness, such as coming out.

Grace says she has been able to pass as neurotypical, which has made things easier for her, because she can act in ways that are more understandable to non-autistic people.

*I used to associate them [conformity and non-conformity] with faking it. And now I associate them with communication....I mean used to be very bitter and think about it as just faking it. And. Not being true to myself. And then I came to realize that, no, what I'm really doing is that I'm communicating in a way they understand... I think of conformity as communication. Funnily enough, that's actually made it a lot easier to do.*

She sees conformity as a way of making herself intelligible. Her view about conformity is interesting, especially as one can see the changes in perspective as she went from seeing conforming as bad to rationalizing how it might benefit her. She also mentions issues around intelligibility to oneself when she talks about being true to herself, demonstrating a need to balance seeking to be understood by others with understanding herself and her own wishes. Grace and Rachel attempt to make themselves understood by changing their behaviour to accommodate non-autistic people, Rachel through disclosing her autism and Grace through conforming to non-autistic norms. Rachel's strategy is different because she may come out to

people so that she can be understood without having to conform. Similar to *Rachel*, *Mikkel*'s strategy for being understood is coming out. He seems to be motivated by its improvement on his mental health and the way being open can help other autistic people. Understanding oneself is a crucial aspect of feeling understood and intelligible. As mentioned earlier, having an autism diagnosis, whether formal or from oneself, is crucial to self-understanding.

### *Diagnosis for Intelligibility to Oneself*

Intelligibility also includes feeling intelligible to oneself. *Sarah* and *Rachel* express how knowing they are autistic has been validating and helped them accept and understand their differences:

*Sarah: It wasn't really until I got into secondary school, and, to put it bluntly, people started being meaner about it, that I then thought "ok, yeah. I do identify. I do actually kind of identify with it." But I'm glad I had the label then, because otherwise I would have realized that I was, you know, different or weird. I'd essentially just internalize what they told me.*

*Rachel: I'm not just a weirdo for no reason. Like, there's a reason for it. And so that kind of validates it a little bit.*

For *Rachel*, realizing she was on the spectrum was validating because it provided an explanation for things she's struggled with. She explains that self-diagnosis lets you own your traits that you used to think were weird. Now she feels like there's a reason for the ways she is non-conforming. Similarly, *Sarah* recognizes that when she was bullied, she would have internalized being different as a negative thing the way *Rachel* did, if she had not known about her autism. *Grace* describes knowing that there was something different about her growing up for a long time before she actually received the diagnosis:

*Well I knew, I've known since a very long time I was growing up that I was not normal. That I did not connect with people the way other people were connecting with them. I didn't do things the other way people do them. I knew that for. As soon as I realized that people didn't act the way I did. But I was not actually given a definition or anything about what I was or why I was until I was about 16.*

Mikkel's experience is interesting to talk about here, because he found out about his autism in such a different way than everyone else, with others around him knowing before he did since he was in special education before he was told the diagnosis:

*I didn't know in the beginning that it was a special school or that I had autism. I just thought it was a small school. I was in. I didn't notice it was different. But then we had a time when our teachers would tell us that we had autism.....And it was a very big shock for me.*

*When I first got my diagnosis, as I mentioned, I was kind of angry, and kind of sad, and confused and everything. And I felt like because I was autistic, then I wasn't as good as other people. So, I didn't want to be autistic.*

In this way, the explanation the diagnosis provided for Mikkel was negative. This contrast between his experience and the others' is interesting, because the others had all felt different for an extended period of time before they learned the diagnosis, and so it may have come as a relief and an explanation. However Grace did feel similar to Mikkel, resenting the diagnosis because, even though she could sense she was different, she wished she was "normal:"

*It was more like the label of normality that I thought I had had been ripped away. Because, I knew I was different. That I was faking it. That I was tricking myself*

*into thinking I wasn't really different. And someone answered "nope, you're autistic." ...Back then, it was something that I resented.*

*Mikkel* likely did not feel the same sense of difference as the others due to being among other autistic children all the time, so the diagnosis did not have this benefit for him and instead informed him that he was different. The way *Sarah* and *Rachel's* feelings about the diagnosis are different from those of *Mikkel* and *Grace* is interesting, as it demonstrates that a diagnosis can both validate people's feelings of difference while also marking them as different in a potentially negative way.

The negative feelings these participants have experienced due to feeling misunderstood and different have led some to look for ways they can expand intelligibility, thus helping other autistic people cope with misunderstandings from society and develop more positive views of autism. Expanding intelligibility and raising awareness of more positive aspects of autism can also help by showing neurotypical people autistic experiences and perspectives they may be unaware of.

### *Expanding Intelligibility*

*Sarah*, *Grace*, and *Mikkel* are all involved in work to expand intelligibility for the autistic community as a whole, in their everyday lives as well as through formal organizations. *Sarah* talks about speaking on a panel at a conference for autistic women and girls, and also writes about autism for a blog along with some other autistic young people. *Grace* wrote a Facebook post about things she likes about being autistic specifically because she feels like people mostly talk about problems with autism and she wanted to share a different perspective:

*Because I realized so many times when people talk about autism, they only talk about problems that they have or they have with autistic people in some ways.*

*And I wanted to write about, you know, the good times. Because there's some people who do enjoy being autistic.*

*Mikkel* tries to expand intelligibility inter-personally in his everyday life. He says one good thing that has come from him being more open about being autistic is that people who have found out they are autistic have started reaching out to him to ask him questions and get support. He says these people are afraid of being misunderstood and are looking for someone to talk to, and being that person for them makes him feel good. In regards to being open to talking with other autistic people, he says:

*When I was not speaking so openly about it, then probably I wouldn't have these kind of conversations with people, because they wouldn't necessarily know that I was autistic, or maybe they wouldn't feel comfortable talking to me about it.*

He hopes that by talking about autism more, especially from the neurodiversity discursive location, *we can make it a positive thing*. *Mikkel's* narrative also fits under the theme of *Terminology*, because through the language he draws from, he is embodying a counter discourse that constructs autism positively. It is interesting that *Mikkel* says we can make autism a positive thing by talking about it. This demonstrates a belief that talking about autism can expand intelligibility for autistic people and thus shape the cultural context they live in.

Similarly, *Grace's* motivation for writing her Facebook post is rooted in her discursive location and a goal of making this perspective more intelligible. She explains that she wanted to write this post after she realized that most of what is said about autism focuses on problems. This desire to spread a less commonly voiced opinion demonstrates a goal of wanting to embody a counter discursive location, as dominant discourse renders her experience unintelligible. She thus uses her modes of expression to expand intelligibility.

*Sarah's* speaking on a panel and writing for a blog expand intelligibility in a similar way to *Grace*, as she finds spaces both on and offline to talk about being autistic, and issues affecting autistic people. *Sarah* and *Grace's* ways of spreading information about autism are different in an interesting way, because *Sarah's* audience is more public while *Grace* is sharing this information with her friends. Both audiences are important to reach, and *Grace's* audience connects what she is doing to *Mikkel's* actions around expanding intelligibility. Yet, while *Sarah* and *Grace* want to raise awareness of their views about autism, *Mikkel's* goals primarily relate to intelligibility in a different way, as he focuses on helping other autistic people feel more understood. *Sarah* and *Grace* are likely helping autistic people through coming out in a similar, though less direct way, to *Mikkel*. Central to these participants' goals of expanding intelligibility is their sense of being connected to autistic community and culture.

### *Community*

A significant subtheme in *Intelligibility* is participants expressing how they feel understood in the context of seeing themselves as part of a community, which suggests that being autistic is not just an individual identity, but also a social one. *Mikkel* has a very direct experience of this from growing up surrounded by other autistic people at his special education school. He says he felt ok being autistic because it was normal at his school, and he didn't feel any different there. This meant that autism was something he didn't even have to think about and he described a feeling of culture shock upon leaving his school for college. Today he feels connected to other autistic people because of his background:

*Even when I was like really hating my diagnosis and didn't want to call myself autistic, I still felt like very connected to the autistic community, because that's where I grew up.*

However, he expresses some tension and contradiction in this view, sharing that when he left his special education school and went to college he felt like he didn't belong in the autistic community he had grown up in:

*I've had troubles with the autistic community. That I didn't quite fit in because, oh I wasn't studying in autistic school anymore and I was doing so well. So I kind of felt like I wasn't welcome anymore.*

This doesn't apply to his friends though, as he says he doesn't need to think about autism or worry about anything around his autistic friends, and also feels understood around other neurodiverse people, such as people with ADHD and bipolar disorder.

Grace, Sarah, and Rachel express feelings of community and understanding among other autistic people, even those they don't know:

*Grace: other autistic people kind of. It depends on whether their autism matches up with my autism, but mostly if not understanding, they are accepting of it. A lot more accepting of it.*

*Sarah: who would understand me? I don't know. Sorry. I guess, like, my immediate thing to say at more broadly is probably other autistic people. Because they existed in the past. And in fiction probably.*

*Rachel: It just feels good to have that as part of my identity. Like, and now I can. I know that I'm part of a group of people that have the same kinds of, of differences with themselves, you know?....It feels good to belong. It feels good for me to belong to the autism spectrum community.*

These participants gain validation and intelligibility by feeling part of a community, and feel like they would be understood by other autistic people. They also feel intelligible by

knowing there are others like them, and so they are not as different as they may have thought before gaining this sense of community. *Grace* also has an interesting way of feeling connected to the autistic community more widely. She talks a lot about the academic, medical, and cultural histories of autism as well as historical figures who were either autistic or studied autism, such as Dr. Hans Asperger, even saying that she is proud to have the diagnosis of Asperger's because it connects her to the history of autism, a unique perspective. It is interesting that *Mikkel* seems to have a more direct connection to an autistic community, while the three others talk about the idea of it. Yet, this idea of community still seems to be validating for them, which suggests that knowing one is part of a community can still be affirming, even without direct contact with others. Even though *Sarah* and *Grace* likely know autistic people and mention being in spaces with others, perhaps *Mikkel* talks about other autistic people more because he has always been primarily around them, a different experience from the other participants.

While it clearly helps these individuals feel understood to see themselves as connected to and potentially understood by the autistic community more widely, this kind of thinking can be problematic because generalizing this whole community risks not recognizing intersectionality and the spectrum of needs and abilities that autistic people have. Furthermore, if individuals who hold this view meet other autistic people and don't feel understood or get along with them, they may feel betrayed and feelings of unintelligibility may be exacerbated. *Grace* says that people use extreme cases of autism to justify wanting to "fix autistic people," saying that really these cases are very rare:

*Yes you managed to find the one out of a million cases that's relevant for your point, but you can't apply the exception to the rest.*



It's important to acknowledge that this view can leave more visibly disabled people behind. With the issue of people talking about autistic people supposedly being so disabled that they cannot like their identities and using this to justify trying to "cure" and "fix" them, I can understand why people in the autistic community may draw on this narrative and discourse. This is an example of a counter discursive narrative around autism. People draw on this narrative because they want to disrupt the dominant discourse that constructs autism as pathology, but in doing so they still exclude some autistic people. They draw on narratives like this as they look for language to express their feelings about autism and the ways they feel misunderstood.

### *Language to Talk about Oppression*

Part of unintelligibility is not possessing the language to talk about one's own oppression. *Sarah* finds that she is unable to express her perspectives about autism and ableism to people. *Mikkel* similarly says he has experienced not being able to explain his views and not having the language to talk about ableism, as discrimination is subtle and hard to recognize. He says:

*I feel like 'ah, why don't you understand how hurtful this is? Like, you're my friend. Why can't you see that this is so hurtful? And why can't I explain to you why it's so hurtful? Why don't I have any tools to explain to you?'*

In special education, he and his friends would talk about experiences they had where they felt misunderstood around autism, but had no language to really name what was going on. Now that *Mikkel* is reading more about autism and neurodiversity, he says he can express himself better. He still experiences not being able to explain how he feels and why things upset him, but he has a better understanding and can talk about microaggressions. *Rachel* is looking for a way to talk about being mentally ill without negative connotations:

*I'm still trying to figure out the best way to like express being mentally ill without it sounding like a negative thing. Because you say mentally ill, that has a negative connotation.....And I haven't, I haven't figured that out yet.*

She is looking for language to express her feelings and identity around mental illness, and similar to *Mikkel* and *Sarah*, she doesn't have the language to name her experiences. However, *Rachel* is looking for language to describe an aspect of her identity, while *Mikkel* and *Sarah* both are looking for ways to describe the oppression they face. All three participants have been searching for language for a long time. *Rachel* is looking for a way to talk about her bipolar disorder, which has been part of her experience for many years. *Mikkel* and *Sarah* both grew up as autistic and are only now finding ways to express how they feel about their identities and experiences. The next theme explores the ways these individuals use language to talk about their lives and perspectives, and how they hear others talk about autism.

## TERMINOLOGY

The terminology people use to talk about autism includes: autism, Asperger's, neurodiversity, and functioning labels, such as low and high functioning. *Sarah* explains how functioning labels are hierarchical and sometimes other terms are used as well to imply hierarchical thinking about autism. For example, she says people will say to her "you're not autistic autistic. You just have Asperger's." It really offends her when people say this, because it's meant as a compliment, but it others people who are deemed "lower functioning." About functioning labels, she says:

*Calling someone low-functioning is kind of insulting and ignores the capability they have. Calling someone high-functioning sounds like a compliment, but it's*

*actually ignoring the very real problems and needs that they face.... And it's unfair. And also, it's inaccurate. People can have all sorts of abilities and needs.*

Mikkel has the same opinion. He was diagnosed with Asperger's, but usually says autistic because he sees the label "Asperger's" as problematic as it creates distance between him and the autistic community as whole, othering people and perpetuating hierarchies:

*I said like I have Asperger's. And then they were like "oh yeah. Ok. So you're like the good kind." And I will. I mean, I will get that as a compliment, but I feel so shitty when I get them, because I feel like "oh thanks. Now you kind of like put down everyone else. Like all my friends who had other autistic diagnoses." And yeah. And I just feel. I just feel bad... I like to actually say that I have autism, because I feel like then people can't really like label me that way as much.*

Sarah and Mikkel both dislike the term "Asperger's" because of its hierarchical meaning, choosing to identify as "autistic" instead because they perceive that as a way to disrupt the dominant hierarchical view of autism, where people are divided into distinct categories of low and high functioning, and valued unequally based on that distinction. Grace, who has an interest in the history of autism, talks about the meanings behind autism and Asperger's and how functioning and passing hierarchies are built into these meanings:

*Dr. Asperger used it as a positive term. Because generally Dr. Asperger looked at the people most able to pass. And Kanner [the psychiatrist behind the label autism] looked at the people who couldn't pass. Who could never have passed at all. They're on the same bracket, but when you take autism, like Asperger's label are the people closest to being neurotypical.*

She explains that these labels historically carry these meanings. This likely influences how people perceive these terms and people who identify or are labelled with them. All three participants' narratives around terminology demonstrate how these terms carry significant meaning, and therefore the terms someone uses communicates their discursive location.

*Rachel's* preferred language differs significantly from the other three participants, and it's important to note that she also has a very different background with her autistic subject position, which may contribute to her differing perspective:

*I think I prefer the term Asperger's a lot... Like, people who have like full blown autism, that really impacts their life and they're disabled by it. There are similarities between me and them, but we're also entirely. It's also an entirely different kind of thing.*

It's interesting that she uses the terminology "full blown autism," which *Sarah* avoids. It seems from the interviews that *Sarah* and *Mikkel* are more involved in autistic activism communities, and notably I recruited these two participants from Facebook groups for autistic people where individuals tend to share these views. *Rachel's* concerns about language she uses for herself seem to be very much based in making sure that her identity is intelligible, which makes sense given that her identity is less secure than the others who have had this identity longer and also have their identities more formalized. She says people won't understand if she says autism spectrum:

*I just prefer Asperger's. And I think. Also, because I think people know what you're talking about more if you say Asperger's. Because if you say autism spectrum, they're like "what is that?" You know "what does that mean?" But if you say Asperger's, they're like "oh yeah, Asperger's."*

She switches between person-first and identity-first language, sometimes using “Asperger’s person” or “on the spectrum.”

The changes around terminology and diagnosing for autism in the Diagnostic and Statistical Manual of Mental Disorders also shape how *Rachel* thinks about her identity. Asperger’s Syndrome used to be a separate diagnosis in the DSM, but now in the DSM V there is only one diagnosis of Autism Spectrum Disorder. *Rachel* shares:

*I’m not offended by the DSM’s choice to group them together. I just kind of think. I just kind of think it would be better if they didn’t do that. And that Asperger’s was still its own thing.*

She says that she will sometimes say “autism spectrum,” even though she prefers Asperger’s, because she worries people will think she doesn’t know what she’s talking about since Asperger’s is no longer a diagnosis in the DSM. The language of diagnosis is an integral part of discourses around autism, as illustrated by *Rachel*’s perspective. While *Mikkel*’s narrative is very critical of dominant discursive language, his language is centred on diagnosis, with discussion of what people’s diagnoses are rather than just their identities and experiences. These findings demonstrate the varied ways these individuals talk about autism, and especially illustrate how they constitute their subject positions through the terminology they use. A significant part of this theme is how language is context specific.

### *Language and Context*

Along with the terminology used around autism by the participants, another subtheme that emerged in interviews was about the language these individuals have observed in different contexts over their lives. *Sarah* expresses how she internalized and then unlearned language attached to dominant discourses of autism:

*When I was at school internalized a lot of the high-functioning stuff. It wasn't until kind of my late teens, that I kind of came to the realization that that was problematic and not helpful for me.*

*Mikkel*, who was also diagnosed as a child, was told he was autistic through his education and so the language he learned the diagnosis through was specific to a special education context.

Language represents particular perspectives and is contextual, which is illustrated by participants describing how they feel about particular terms and the context where they hear them. *Sarah* says language can have different meanings based on who is speaking. “Different” can sound patronizing coming from a neurotypical person, but empowering coming from a neurodiverse person. Similarly, *Mikkel*’s feelings upon hearing the term “autism” depends on the context:

*It really like depends so much on context. Like, for me, when I think of autistic, I think of all the associations I had. All the. Like, I think of myself and my friends. I think of my school. I think of people in my class...But, if I just hear it randomly somewhere, someone saying it in school. And I'm not sure of the context, then I sometimes get a little nervous. Because I know that sometimes people also use it as a slur word.*

If he or a friend is talking about autism, it has a neutral meaning. However, if it’s someone he doesn’t know, the term may have a different context and meaning.

*Rachel* says people only really talk about Asperger’s when she brings it up, so she doesn’t hear it much and she doesn’t hear it talked about negatively. However, as *Rachel* is mentally ill, her feelings about discourses around mental illness more broadly are interesting to discuss here. She describes how she feels very upset when she hears anyone say “crazy” and

“psycho” because these terms have been used aggressively toward her in the past. Now she finds that while the term “mental illness” has negative connotations, people use it in a respectful way and she hears helpful conversations about it. She hasn’t decided what terms around mental illness she wants to use, though she’s used “mad proud” occasionally and likes that. Both *Mikkel* and *Rachel* worry about language and context because they have experienced particular terms having negative and stigmatizing meanings. *Rachel* and *Sarah* share the process of changing the language they use as they move through different contexts. Stigma and negative views of autism are a big concern for all three participants, and this demonstrates the discrimination autistic people face. *Rachel*’s views about language for mental illness brings us into a discussion about the term neurodiversity, which refers to mental illnesses and differences beyond autism.

### *Neurodiversity*

I asked participants to share their associations with the term neurodiversity and how they use it when talking about autism and other neurodiverse identities. *Grace* defines neurodiversity as an umbrella term, like queer and LGBTQ, though when she talks about it, she’s usually just talking about autism and she doesn’t identify as neurodiverse herself. *Rachel* doesn’t use neurodiversity much because she is usually specifically talking about Asperger’s. *Mikkel* has more experience with the term and finds it meaningful and helpful, though he does not feel like he knows a lot about it, saying he has mostly read about it on the internet. He likes it because it is political and critical, and is about challenging norms:

*And I feel neurodiverse is kind of like a bit the way I feel about queer also. Where I come, from queer is kind of like a broad term that kind of means critical... And I feel the same with neurodiversity. That it's this big broad term that's kind of like you don't really define specifically like what you have. It's more like the thought*

*behind it is more like the meaning what you think. Like, you're kind of critical of the way people before have thought of these things.*

The term neurodiversity, and the discourse attached to it, is particularly positive for him, because he grew up having internalized the medical discourse around autism, which he describes as a negative, pity discourse. Finding a counter discourse that challenges the one that constituted his subject position growing up has been empowering for him.

He was introduced to the term by a psychiatrist, which is interesting because psychiatry exists in a medical context. Learning this new language along with encouragement from the psychiatrist lead him to develop a more affirming perspective about his autism. He comments that it is odd he never heard about neurodiversity while he was in special education. He also doesn't hear the term used in his community, even among activists, although lots of people talk about autism. He identifies as neurodiverse depending on the context: using autism if he's talking about traits or experiences specific to that; neurodiverse for issues that those with different neurodiverse identities would relate to, such as struggling with school; and just using autistic sometimes if he thinks people won't know what neurodiversity means.

Participants do not use the neurodiversity term when talking specifically about autism and Asperger's because neurodiversity refers to all mental disabilities. The differences between participants' awareness and use of the neurodiversity term, suggests that the counter discourse attached to it is still largely unintelligible. For example, *Mikkel* says that he does not hear it used at all, which demonstrates how it still remains unintelligible in comparison to popular and dominant terminology.

Language and discursive meaning shape these individuals' realities and the ways they feel intelligible. The next theme connects back to my previous discussion of diagnosis.



Receiving a diagnosis involves autistic people's identities and experiences being medicalized.

Medicalization pervades the lives of autistic and other disabled people.

## MEDICALIZATION

Autistic individuals experience medicalization throughout their lives, which can be positive as well as detrimental. Participants talk about the processes of medicalization they have experienced in different contexts, such as therapy, education, and medical contexts. *Sarah* discusses her experiences of navigating autism in academic institutions, which she has to do in order to get an assessment to get diagnosed. These experiences include meeting with counselors and disclosure, which she explains is complicated for her because she does not yet have a formal diagnosis. She expresses a lot of anxiety about navigating these spaces in her universities, but says that all her experiences have ultimately been positive. Her need to obtain a formal diagnosis demonstrates a way that medicalization can be helpful. Autistic and other disabled people need diagnoses to access accommodations in school as well as other resources. *Rachel* also comments on the medicalization that happens in educational contexts, but in this case is talking about elementary school contexts:

*I really think that if my brother and I were like, you know, in elementary school today, in, you know, today's society where teachers are more aware of autism issues, I think we would have been pulled aside, and our parents called, and said, you know, "we think your child has autism, or Asperger's."*

School is often a context where autism is first recognized in children, though *Rachel* says this likely did not happen with her as there was less awareness in the 90s. *Sarah* had the experience *Rachel* describes, where her teacher told her mother that she might be autistic. *Mikkel* had a similar experience, having grown up in special education at a school for autistic children. It's

interesting that although there was less awareness in the 90s, both *Sarah* and *Mikkel* were labelled as autistic early. This demonstrates complexity in awareness of autism over time, as well as the complexity of autistic people's experience. It is worth noting that *Rachel* grew up in the United States, while *Mikkel* and *Sarah* grew up in Europe, which may be significant. *Rachel* is also slightly older than *Mikkel* and *Sarah*.

Outside of academic institutions, two contexts where medicalization occurs are through therapy and in doctor's offices. *Rachel* and *Grace* had positive experiences with therapists. *Rachel's* therapist is very open and validates her identity:

*I've talked to my therapist about it, and she didn't seem to have a strong feeling of "yeah, I think you have it, or yeah I don't." She was just accepting of what I thought.*

*Grace's* therapist in university helped her navigate resources, telling her about an autism group where she was connected with community and resources to understand being autistic. She also maintains contact with her high school therapist and feels understood by her, so it is clear that like *Rachel*, she has had positive experiences in therapy. Though *Grace* has only really talked about autism with therapists, she thinks a different discourse would be present in psychiatry. Although, through *Mikkel's* narrative we can see that this might not necessarily be the case. *Grace's* assumption about that suggests a belief that psychiatric contexts are more medicalizing than therapy contexts.

In contrast to positive experiences in therapy, participants express more conflict around medical contexts. *Rachel* says she hasn't told her doctor about her Asperger's identity. *Mikkel* feels out of place around doctors and will not talk about autism around them. This is connected

to an upsetting experience he had where he was denied medical gender transition because sometimes autistic people are not allowed to transition:

*They didn't want to deal with me because I had autism. And then when I went in there, they asked me what autism was, the first time....And then when I went back some years later, to get, again try to get that permission for treatment, then I got the same therapist as I had last time....She kind of asked if I, if I had been cured. And I was like "no." But at the same time, I didn't want to try to step too much into it. Because I knew if I said something, like that I was very neurotypical, then she would give me permission for starting hormone treatment.*

*Mikkel* was placed in a situation where he had to negotiate his openness about his autistic identity in order to avoid being medicalized, and possibly denied medical transition a second time. The therapist also seemed to lack knowledge about autism, believing it could be cured.

Despite these problems with medicalization, it is a necessary part of getting a formal diagnosis, which many autistic and otherwise neurodiverse people need. *Mikkel* explains how he hopes to get a diagnosis for dyscalculia soon, which he likely needs to access accommodations in college. Even though *Rachel* is uncomfortable talking to a doctor about having Asperger's, she still wants to get a diagnosis because she believes that a formal, medical diagnosis will give her more legitimacy. As illustrated by these findings, subjectivity is shaped by experiences of medicalization, particularly because of the significant impact receiving a diagnosis has on the constitution of subject positions.

## IDENTITY

Participants express a tension between wanting their autism to be recognized as an integral part of who they are, while also wanting people to recognize their identity beyond being autistic. *Sarah* expresses several times that she wants there to be a balance between people acknowledging and understanding that autism is part of her identity and also seeing that there is more to her identity than being autistic:

*I don't want autism to define me, but a lot of the time when people say "don't let autism define you," they mean ignore it completely. You know. And that's not possible. That means be someone else. And I don't want to be someone else. I want people to, you know, understand who I am, including, including that I'm autistic... But, I want them to kind of understand that that adds up to a whole.*

*Mikkel* also talks about how he doesn't want to be seen as just autistic, while autism is still part of his identity and how he lives his life. He describes the tendency for people to view autism in a black and white way where they see autistic people as either having sad lives where they can't do anything or seeing them as inspiring in their abilities, asserting that he doesn't want to be put in these boxes. He says:

*So, I want people to see me as a person that is successful, but not successful in that way of how to be like a success story successful. But more like successful in my own way, that I can kind of rest in my own skin. That I can be openly autistic. I can have issues and troubles, but I know how to deal with them. And the things I want to do in my life is not holding me back.*

*Mikkel* and *Sarah* express wanting to be themselves, a complex topic that demonstrates the agency they seek with their identities.

Another aspect of this theme that came up in people's narratives was how strongly they identified with being autistic, which I discussed earlier under *Diagnosis* and also addressed within the subtheme of *Diagnosis for Intelligibility to Oneself*. *Rachel* and *Sarah* especially feel attached to having this identity, most likely because, unlike the other participants, they have not yet had a formal assessment so there is still a chance they could be told they are not autistic. They are both very anxious about this. The possibility of this brings up a bigger question in regards to identity of what it would mean to be told you are not something you identify with, which should be addressed in future research on autism. This label is important to them because it validates and explains their reality, especially the ways they feel different. It provides a framework and a language to describe their experiences. Additionally, as previously discussed, identifying as autistic provides a sense of community and consequently a level of stability to their experiences.

Having this validation for experience and difference is especially important for *Rachel* who has felt stigmatized for differences due to her mental illness. She talks about mental illness and autism being connected in that they are both identities she didn't choose and aspects of who she is that are never going away. However, she feels that despite that, her identity around them and her perception of them might change, and so they may have a different effect on her in the future. While her autism is an aspect of her identity that she really likes, she struggles more with her mental illness and often wishes it would go away.

At the root of these narratives is a strong desire to constitute their subjectivities, and they likely have been lacking this agency for much of their lives. It is notable that both *Sarah* and *Mikkel* were diagnosed as autistic at a young age, so their autistic subject positions have always been medically constituted. However, their autistic subjectivities have changed over time as they

resist subjectification within dominant discourse. *Sarah* is now worried that this label she has constructed her identity around could be taken away from her, even though it was imposed on her initially. For *Rachel*, constituting her subjectivity means being able to claim this autistic identity through self-diagnosis and hopefully eventually through a formal diagnosis, but this would also be on her own terms.

In looking at participants' narratives of the issues around identity and unintelligibility they have struggled with throughout their lives, a theme emerged that dealt with changes. As discussed in previous chapters, the reason I chose to interview people in their 20s was that they have likely experienced varied discursive and social contexts throughout their lives. The following theme looks both at their hopes and worries for the future, as well as at changes they have experienced around feeling understood and their diagnosis.

## LIFE COURSE

### *Changes in Feeling Understood*

Participants compare feeling understood currently to how they felt growing up and reflect on the future. They say their lives are much better now and they feel more understood. *Sarah* talks about how in high school she was bullied and treated badly, but once she got to university things really improved. *Grace* feels more understood now than she has before and also feels like she has more access to media and resources around autism. *Mikkel* and *Rachel* have similar experiences with feeling understood, and their narratives are interesting because they demonstrate complexity in what it means to be intelligible. They both feel that in some ways things are worse now for them in terms of feeling understood, but they say this could be because they are more open now and thus more vulnerable to rejection. *Rachel* says in the past year and a half, she's lost a lot of friends, but also has more friends who really understand her, explaining:

*I'm more than ever, any other time in my life, I'm better able to express who I really am. So, even. But at the same time, I've also had a lot more rejection during this time of my life. So maybe that's related. You know, maybe because I'm able to better express myself, more people are able to say 'oh, yeah. That's great.' And more people are able to say 'I don't want you in my life' or 'I don't like being around you.'*

She also says that over time she's gotten better at holding her ground and standing up for herself when people do not believe that she is autistic. *Mikkel* says:

*I feel the last few years it has been worse. But I don't think actually it has been worse. I just feel that it's more that I made a decision that I wanted to be more open-minded and more outspoken that I have autism. So, not only if people said something directly to autism, but just in general conversation I will be more like "yes, I have autism. Therefore, blah blah blah." And of course, I receive like comments for that.*

He gets negative comments about being autistic more often because of his openness, which makes him vulnerable. He also understands ableism better now, so he notices it and calls it out more. Participants' narratives demonstrate that access to more resources and community can help with feeling more understood. They mention learning more about autism, which helps them be more open, and this openness helps them find community. As they experienced changes in whether others understood them and their autistic identities, their own feelings about being autistic have changed as well.

### *Changes in Feelings about Being Autistic*

Ways these participants have felt about their diagnoses and identities are influenced by various factors, such as when, or if, they were diagnosed and how they were told. As previously discussed, *Sarah* very much identifies as autistic now and is involved in advocacy. *Grace* and *Mikkel* have experienced significant changes in how they feel about their diagnoses over their lives, but interestingly *Sarah* never seems to have had the negative view of her diagnosis that they had and *Rachel* says she has no negative associations with autism.

In an opposite experience, *Grace* says she hated the diagnosis because it confirmed that she was different and “not normal.” Similarly, when *Mikkel* learned about his autism, he resisted and rejected the diagnosis. Eventually he started to see his autism in a neutral way and says his current views are much healthier, and though he still has anger around autism, he has learned to direct that towards ableism and oppression and not at himself for being autistic. This change happened after a psychiatrist encouraged him to explore his feelings around autism and introduced him to the neurodiversity discourse:

*She kind of started to make me like. Make suggestions of like looking into this topic, like all this like anger I had. Not some on myself, but also like on society. And how I felt bad treated. And so, I kind of start doing that. And I kind of changed my anger from being, like putting a lot of pressure on myself. And like not wanting to be autistic. And instead being like, "it's ok if I have autism."*

After that he stopped seeing autism as a bad thing and started identifying as autistic. When he was in special education, autism felt like a label he and his classmates had, but now he has come to see it as an identity, especially as he sees the ways in which he is different from his neurotypical friends and can see those differences as not a bad thing. *Grace's* views about her



diagnosis are also much more positive now and she feels more self-acceptance. She also says that the more she accepts not being neurotypical, the less autism feels like a label imposed on her. Her views changed in her second year of her undergraduate degree when she joined the autism group her therapist recommended.

It is interesting that both *Grace* and *Mikkel's* changes in perspective were facilitated by a therapist or psychiatrist, as this involves their subjectivities being constituted in medicalizing contexts. *Rachel's* lack of negative feelings about being autistic is interesting because her experience of coming into the identity on her own is different than all the other participants. She has had more agency over this identity, never seeing it as a label, which may contribute to her positive feelings about it. *Grace* and *Mikkel* very much saw autism as a label imposed on them, which likely contributed to their negative feelings about it, but possibly due to other factors in *Sarah's* life she does not describe the same feelings they had.

#### *Hopes and Fears for the Future*

Participants also look towards the future and think about what their lives may be like based on their experiences so far. *Sarah* expresses worry about her future, especially in regards to responsibilities of being an adult and social pressures to have a specific career and other expectations. She worries about being taken seriously as she struggles with some parts of her autism. When she did a study abroad in Paris, she was more independent and away from her support network, and the stress she experienced during that time made her fearful about her future. She expressed concern about getting a career and living in the *real world*, especially as autistic people tend to have more difficulties finding jobs:

*Being a young person, at the moment, in the kind of job climate, the general climate, is just really scary anyway. But autistic people obviously will face, can*

*face additional barriers. I think in the UK it's something like only 15% of autistic people are in full-time employment. That's quite an old statistic. I don't know how true that stands now. But, you know, you see those statistics and it does worry me. You're thinking "oh, wow. You know, all I've done so far is study. Sooner or later I'm going to have to hit the real world and I don't know how I'll deal with the real world."*

Since she's in law school, she experiences a lot of pressures to take particular routes with her career and feels anxious because she doesn't know what she wants to do yet. She also feels pressure around expectations to marry and have a family.

*Mikkel* feels similar pressures and expectations for his education and career, saying that people have narrow ideas of what it means to be successful and that he often feels his life is being questioned:

*I wish people could understand that there's like other ways to be successful and, yeah, live your life. Like, people expect you to like do a certain thing. Like, go to school. Then get good grades. And get a full time job, and so on so on. And when I say like "I'm not sure if I can finish this education. I'm not sure if I will ever be able to have a full time job," then it's like, then they don't know what to say.*

*Rachel* worries about her professional future because she can't easily regulate how she feels and acts due to her autistic and bipolar traits:

*It sucks because I think, in order to be a professional, like a professional person, you have to be really good at being something other than what you actually feel. And so I worry about my professional future a lot.*

She hopes to find a career where she can have less interaction with others and won't *have to be something to anybody*. These are already issues that young people deal with often, but these feelings may be more intense for autistic people because they may struggle with things that other young adults don't, and also face ableism and misunderstanding. As has been demonstrated throughout this chapter, feeling understood is a significant concern for these individuals.

This worry participants share about careers and the idea of being “successful” is interesting because this suggests that they may have internalized ableist ideas about what they can contribute to society and their value as individuals. For example, *Rachel* is concerned that she will not be able to be professional because of her autism and bipolar disorder. Besides fear about whether they can be successful, another place internalized ableism can be seen is in their feelings of responsibility for whether others understand them.

#### INTERNALIZING RESPONSIBILITY

Another theme that emerged during coding is around participants feeling responsible for others understanding them, which is interesting and important because it demonstrates how these individuals have internalized their feelings of difference, even as they express positive and affirming views about being autistic. As autism is characterized by having trouble with social skills, participants may have internalized the idea that any misunderstandings they have with people are a result of their autistic traits. *Rachel* talks a lot about how she will disclose to people to avoid miscommunication and explain awkwardness, even in scenarios where it sounds like the other person involved could be just as responsible. She talks about needing to “warn” employers about her autistic traits and says her bipolar disorder is *the culprit* in people not understanding her. *Grace* says she tries to be helpful to compensate for certain things, demonstrating that she feels she has to make up for her autism:

*I was like maybe if I'm helpful enough, it will compensate for this. Let's hope that I'm helpful. It will compensate for this.*

She talks about herself as being “rude,” and seems to be trying to own this aspect of herself, as she could be seen that way by others. Though she does not mind being seen as rude, she feels upset about times when she burns bridges by accident. She worries about losing control of her ability to communicate with people when miscommunication happens. Similarly, *Rachel* talks about not being able to change people’s minds and fix things when they get the wrong impression of her.

*Sarah* says that whether people understand her is dependent on whether she is open with them, and even how well she understands herself. *Rachel* says she has more friends now who are able to understand her because she is able to express herself and explain her traits better than she had been in the past. Similarly, *Grace* says she’s more understood now because she’s learned how to explain her differences to people. She describes how:

*I think I feel most. Like, most understood now in my entire life because I'm starting to be able to bridge the gap between myself and people who don't know me. Learning to be able to actually talk about how I'm different and explain it to people. And. And in that process things are going much further than they were.*

While *Rachel* expresses this sentiment a lot in her interview, she does at one point start to take that responsibility off herself more when she says she wishes *people were better able* to see the difference between her bipolar disorder and her personality. The use of the word “able” is interesting here because of its association with disability. *Mikkel* reflects on how he feels pressure from society to compensate for being autistic, echoing *Grace*’s feelings:

*I have to better myself, in a way. And that pressure of being a little bit better than everyone else, or at least be trying to be as good as them, or something like that... I think that feeling that can sometimes like make you lose a bit of a part of yourself.*

By saying this, he is pushing back on the idea internalized by participants that they have a responsibility to conform with and communicate with neurotypical people, rather than neurotypical society accommodating them.

This theme is important because it shows how the dominant discourse constructing autism as negative can be internalized by individuals, to the extent that this view remains part of their self-image even as they experience other positive changes. The connection this theme has to *Terminology* and *Intelligibility* is an example of the interconnections between the themes discussed in this chapter.

These narratives demonstrate the complexities in how these individuals feel about being autistic in a cultural context where the dominant and counter discourses surrounding autism shape their identities. Even beyond identity and self-image, cultural perceptions of autism have very real implications for these individual's lives, such as influencing whether they experience discrimination as well as the opportunities available to them in terms of education and careers. In the following chapter I will connect these findings to post-structural theory and previous research on autism, to show how these individuals' narratives add to our understanding of autistic people's perspectives and the ways they experience having this label in our current cultural context.

## Chapter 5: Discussion

This chapter looks at how my research supports, differs from, and builds on post-structural theory of disability and the previous research outlined in my literature review. Also central to this chapter and the conclusion of my thesis is a discussion of limitations on my research and findings, ideas for future research, and the significance of my research for the wider study and understanding of autistic people's identities, experiences, and perspectives.

Throughout my thesis I have drawn from different epistemic positions, including post-structural as well as more modernist and psychological lenses. Employing diagnostic terms and addressing psychological experiences, such as discussing feelings in relation to mental health, does not fit within a post-structural framework. Yet I found that as I was thinking about my data and writing this thesis, I kept coming back to using these modernist terms, and so did my participants. While the concepts of identity and diagnosis are modernist, they seem very difficult to get away from, and people's potential attachment to these concepts is important to address. It may be that people have difficulty conceptualizing their experiences without using this language, and it seems useful for them to draw from psychology when talking about their mental health. None of my participants talked about their experiences through a post-structural lens, and I wanted to represent their own use of language, rather than impose post-structuralist language on their narratives and experiences.

I have decided to include modernist and psychological epistemic positions in this thesis because of their prominence in my participants' narratives. I employ post-structuralism for the theoretical component of my thesis, because I am exploring discursive constructions of autism and the constitution of people into subject positions. I have found post-structuralism to be particularly useful in understanding the multiplicity of discourses surrounding autism.

## DIAGNOSIS

Findings within the theme of *Diagnosis* demonstrate diversity in participants' experiences of when and if they received a diagnosis. My findings differ from Huws and Jones' assertion that those with Asperger's tend to receive a diagnosis later, with many being diagnosed as adults (2008). As Huws and Jones' research is from 2008, this could demonstrate changes over time as there has been increasing awareness around autism, due to a significant increase in information about autism on the internet.

The experience of self-diagnosis is significant in my findings, which reflect previous literature from Lewis (2016) and Bertilsdotter-Rosqvist (2012), such as that adults in Lewis' research were self-diagnosed for an average of 3.25 years before they received a formal diagnosis and that people would become more confident in their self-diagnosis as they researched symptoms and traits (Lewis 2016). However, my research differs from Lewis' finding that people experienced some denial upon learning negative things about autism. Lewis found that some self-diagnosed people never felt the need to get a formal diagnosis. However, others wanted one because they needed accommodations or they were worried about people not believing them (Lewis 2016). Participants in my research also felt this.

This discussion of why self-diagnosed people seek a formal diagnosis brings us to a discussion of the differences between identity and diagnosis among autistic people. My participants share perspectives found in previous research. In Brownlow and O'Dell's research, participants challenged the prioritizing of medical knowledge within the dominant discourse, and in Bertilsdotter-Rosqvist's research participants saw themselves as holding legitimate knowledge about autism that should be acknowledged, though they also viewed medical knowledge as important (Brownlow and O'Dell 2006; Bertilsdotter-Rosqvist 2012). My participants'

comments also reflect Straus' view that autistic people should be free to identify as such, without being labelled by a medical professional (Straus 2013).

My participants' questioning of whether they can identify themselves as autistic, without a formal diagnosis or even after being told they are not autistic, reflects post-structural theory on knowledge and power relations. The dominant discourse constitutes medical knowledge as the most legitimate and necessary to constitute disabled subjectivities. My participants are constituted within this dominant discourse and struggle over whether they can constitute themselves as autistic based on their own knowledges (Goodley 2007; St. Pierre 2000).

There are more connections between my results and previous research on experiences around receiving a diagnosis besides self-diagnosis, but I will discuss these later in connection to the theme of *Life Course*, because the experience of being diagnosed at a young age is particularly relevant to that theme. As previously mentioned, a significant reason for getting a formal diagnosis is to be understood by others and to have one's identity legitimized.

## INTELLIGIBILITY

Several subthemes emerged for the theme of *Intelligibility* in my research, and for this comparative discussion these can be divided into two groups: misunderstanding and understanding.

### *Misunderstanding*

My research supports Mogensen and Mason's finding that individuals expressed difficulties interacting with others and saw these social difficulties as an impairment linked to autism (Mogensen and Mason 2015). However, instead of feeling that their social difficulties are a result of an impairment, my participants feel that society and people around them misunderstand them and their autistic traits, which seems to be a major way they feel



misunderstood. This experience reflects post-structural theory on subject positions constituted within counter discourses being unintelligible, as the ways these individuals express their subjectivities are not understood by others (St. Pierre 2000). They sometimes internalize fault for social difficulties, but they mostly express feeling misunderstood within neurotypical culture and norms. A significant part of this misunderstanding is around being disbelieved and having their autism questioned.

My findings parallel previous research from Bertilsson-Rosqvist, who explains that even people with formal diagnoses experience disbelief from others when they come out as autistic, which happens because of the stereotypes people hold about what autistic people are like (Bertilsson-Rosqvist 2012). My findings also reflect Lewis' assertion that one of the reasons self-diagnosed people seek a formal diagnosis is that they worry people will not believe them when they come out (Lewis 2016). A key reason that autistic people experience disbelief from others may be that due to stereotypes of autism as negative, people think they are "being nice" to autistic people by doubting them, but this actually just makes autistic people less likely to come out (Bertilsson-Rosqvist 2012). The issue of people doubting autistic people possibly because they do not fit stereotypes relates to theories about performance of subject positions. Individuals who are disbelieved are not performing the discursively dominant subject position, so they are unintelligible as autistic (Tremain 2001). My research supports Bertilsson-Rosqvist's findings and demonstrates how upsetting this disbelief, doubting, and questioning is for autistic individuals. This problem with stereotypes and disbelief shows the extent to which autism is misunderstood. This connects to post-structural theory of subjectivity and subject positions, because there is a conflict in the constitution of their subject position as autistic. They may feel a

lack of agency as their subjectivities are being constituted by others in opposition to their own knowledge (Goodley 2007; St. Pierre 2000; Tremain 2005).

My research also supports Mogensen and Mason's finding that stereotypes and stigma around autism increase the difficulties some young autistic people have in their social lives (Mogensen and Mason 2015). Others' lack of knowledge and stereotypical ideas about autism affect these individuals in their daily lives by, for example, making them apprehensive about coming out to people. My finding that medical professionals can also misunderstand autism and autistic people builds on Mogensen and Mason's research. However, my findings also demonstrate that medical professionals often are understanding. This suggests that people who are part of autistic and neurodiverse communities, such as on the internet, may hear about others' bad experiences with medical professionals and then feel anxious themselves. *Sarah's* narrative especially suggests this, as she expresses having felt anxious and then says her experiences went much better than she had expected. Living with this worry around being misunderstood likely has a negative impact on quality of life. The distress my participants experience about being misunderstood illustrates the difficult work people must do as they negotiate subject positions, constituting themselves through different discourses (St. Pierre 2000).

Importantly, Mogensen and Mason assert that having this anxiety about coming out and controlling self-expression can have a lasting negative impact on mental health (Mogensen and Mason 2015). My research builds on these findings by demonstrating the distress individuals experience as a result of the misunderstanding they face from peers and society as a whole. My findings also support Lewis' research on the feelings of difference experienced by people before either formal or self-diagnosis, who do not know they are autistic. These individuals know they

are different, but because they do not know why they may isolate themselves and have low self-esteem (Lewis 2016).

Unintelligibility can also be experienced through internalizing discourses that construct one's identity as negative, and this can happen with deficit and pity centred discourses. My research supports Bagatell's assertion that identity construction is shaped by learned discourses as well as Baines' findings that societal ideas about disability shape sense of self (Bagatell 2007; Baines 2012). My findings also demonstrate how participants have been constituted in a discursive context that medicalizes their behaviour, and since they have internalized this medicalized subject position, they govern themselves based on disciplinary power (Goodley 2007). This particularly relates to the previously mentioned experience of participants feeling at fault for social difficulties, as constitution within a medical discourse of autism constructs how they view their interactions and may lead them to blame themselves based on ideas they have internalized about being autistic. Findings from my research as well as previous literature demonstrate the harmful impacts that being misunderstood and unintelligible can have on autistic people's self-esteem, sense of self, and mental health. In contrast to the harms caused by misunderstanding, my participants share how others' understanding has strong positive effects on their happiness and self-worth.

### *Understanding*

The experiences of my participants around feeling understood, such as when people are willing to listen and not make assumptions, build on Mogensen and Mason's findings about connections between self-acceptance and acceptance from others (Mogensen and Mason 2015). Since being understood is so important to autistic people's self-esteem and well-being, they have to negotiate this and find ways to make themselves understood.

My participants share the value in being open about being autistic expressed by participants in Bertilsdotter-Rosqvist's research, along with the concerns they acknowledge about negotiating misconceptions (Bertilsdotter-Rosqvist 2012). My findings differ from previous research demonstrating autistic young people attempting to pass as neurotypical in order to influence how others perceive them and because they worry about being accepted due to stigma (Baines 2012; Mogensen and Mason 2015). One of my participants sees conformity as a form of communication rather than a way to pass as neurotypical. This is interesting in how much it diverges from previous research on conformity or "passing," as it is more about managing inter-relations rather than keeping something a secret.

A crucial aspect of feeling understood is understanding oneself. Diagnoses can also help with self-acceptance and understanding. Huws and Jones (2008) and Mogensen and Mason (2015) discuss the idea of autism as an "absent presence," and this experience of both being aware of their differences but lacking an autistic identity or label was shared by half of my participants for part of their lives (Huws and Jones 2008:102; Mogensen and Mason 2015). My findings also support Mogensen and Mason's assertion that it is important for people to know about their autism, as well as Lewis' finding that self-diagnoses can provide an explanation for differences (Mogensen and Mason 2015; Lewis 2016).

Autistic people negotiate being understood at the individual, inter-personal level, but this is also connected to how autism and autistic people as a group are understood in society. My research supports Bertilsdotter-Rosqvist's and Mogensen and Mason's findings about autistic people challenging stereotypes in their lives and during their interviews (Mogensen and Mason 2015; Bertilsdotter-Rosqvist 2012). Research around actions autistic people take to challenge stereotypes and help other autistic people demonstrates how people see themselves as part of an

autistic community and possibly as activists, which can also help them feel understood. My participants' belief in the importance of sharing their views about autism and helping autistic people to be better understood supports McGuire's argument that narratives from autistic people expand intelligibility (McGuire 2016). The sense of community my participants feel about other autistic people could be described as seeing autism as a culture, as argued by Straus (2013).

Through this sense of community people may develop a shared sense of identity, and having a label or term for differences can help with constructing identity. My research supports findings demonstrating that a label validates people's differences and can show them that there is a community of people like them (Mogensen and Mason 2015; Bertilsdotter-Rosqvist 2012). However, it is important to note that some feel outside of this community and my research also supports Bertilsdotter-Rosqvist's assertion that a counter discourse constructing an autistic normalcy can exclude autistic people who fall outside of it (Bertilsdotter-Rosqvist 2012). The problem with constituting oneself as part of an identity based group reflects theory from St. Pierre about identity politics, which will be discussed shortly (St. Pierre 2000).

One place autistic people find community is on the internet (Lewis 2016). My research supports findings that autistic people use online spaces to express views counter to dominant medical discourses about autism (Ward and Meyer, as cited by Brownlow and O'Dell 2006).

## DISCOURSE

The theme in my research of *Terminology* connects to previous research in what it reveals about the discursive locations individuals embody. By questioning and rejecting diagnostic terms, my participants challenge dominant medical discourse in similar ways to the participants in Bertilsdotter-Rosqvist's study (Bertilsdotter-Rosqvist 2012). Although one participant employs a dominant discursive location, it is important to note that as she recently began

identifying as autistic she may have less access to communities where these counter discourses are produced than the others. Her drawing on a dominant discursive location reflects the post-structural argument that we use the language available to us based on our constituted subject position (Goodley 2007). Also, this participant's narrative supports Parsloe's assertion that autistic communities are intrinsic to the development of these counter discourses. Unlike individuals in Parsloe's research, most of my participants do not draw on the term Asperger's, even though this was the diagnosis they received (Parsloe 2015). My findings build on research around terminology used by autistic people, as my participants describe the ways terminology actually changes meaning based on context (Dekker 2000, as cited by Brownlow and O'Dell 2006).

Terminology has changed meanings and new terms have been created through the neurodiversity discourse, which was described as helpful by participants in Griffin and Pollak's research, particularly in that it improved their understanding of their diagnoses (Griffin and Pollak 2009). My research supports these findings and builds on them, as some of my participants see neurodiversity as also a political term, which highlights the purpose of neurodiversity as a counter discourse. Participants also express how language can take on different meanings based on context and who is speaking, which reflects post-structural theory on unstable connections between language and meaning (St. Pierre 2000). My participants share the experience of those in Parsloe's research who reclaimed their autistic identities, deconstructing dominant discourses that constitute autism as negative pathology (Parsloe 2015).

## MEDICALIZATION

The dominant medical discourse around autism that constructs it as a deficit is central to medicalization. Interestingly, none of my participants mentioned medical interventions addressed

in previous research, such as Applied Behaviour Analysis, which is why I am not discussing them in more detail (Mogensen and Mason 2015). While my participants did not talk about medical interventions specifically, they did talk about internalizing medical discourses as children and the negative effect this had on them, which supports Mogensen and Mason's research on this same issue (Mogensen and Mason 2015). This connects to post-structural theory on the constituting of subjectivities within particular discursive contexts. These participants internalized medicalized subject positions (Goodley 2007). Though some experiences participants have in medical and therapeutic contexts can be detrimental to autistic people's self-esteem, all of my participants described having positive and affirming interactions. My findings expand on previous literature by also looking at people's experiences of navigating institutions of medicalization, such as the process of obtaining a formal diagnosis and being autistic within academic institutions. Internalizing discourses, through processes like medicalization, influences autistic people's perspectives about autism and themselves, thus shaping their identities.

## IDENTITY

My research supports Baines' assertion that individuals perform identity in order to navigate their social contexts and negotiate others' perceptions of them, and that young people desire agency in shaping people's perceptions of them (Baines 2012). Post-structuralists argue that subjects are constituted into categories of identity and Goodley describes how individuals resist this categorization, a negotiation that is reflected in my research with my participants expressing tension over wanting to be seen as autistic, but also wanting to be recognized as more than just autistic (Goodley 2007). In my participants' narratives, they express resistance to their discursive constitution as autistic subjectivities and the attached meanings. However, the way they resist is to take on new subject positions, such as "being neurodiverse," which reflects how

people cannot abandon their constitution within subject positions. In resistance they draw on and reject subjectivities, but always exist among them (Goodley 2007; St. Pierre 2000). Also, the concern the participants without formal diagnoses express about possibly being told they are not autistic reflects the way subject positions provide meaning (St. Pierre 2000). For example, *Rachel* says that without the autism label she is “just weird.” Being constituted as autistic gives meaning to her experiences in a way that is validating.

While people experience these tensions around discursive constitution, being in between subject positions may cause anxiety and uncertainty, which can be seen in the undiagnosed participants’ fears of being constituted as not autistic within medical discourses. Yet, here we can also see them resisting discursive classification, as they would then identify as autistic while not being medically discursively constituted as such. Perhaps the pressure in modernist discourse to have a fixed identity is what causes their anxiety around the potential lack of a medical autism diagnosis. Goodley argues uncertainty is valuable, as it is helpful in destabilizing the modernist view of identity as fixed and stable (Goodley 2007; St. Pierre 2000).

St. Pierre’s assertion about modernist discourse grouping people into broad categories, such as women, and thus ignoring difference is also supported by *Mikkel’s* experience of not being able to express his autistic and transgender identities simultaneously. The dominance of modernist identity politics also explains why *Grace* and other autistic people may generalize about the autistic community in ways that overlook people’s differences. The disability rights movement, as well as the feminist movement, has in the past tended to use these identity categories as central to their activism, a way to unify the movement around rights for a specific group. The generalizations made by some autistic people about the autistic community as whole



demonstrates St. Pierre's argument about the potential for this identity based discourse to be exclusionary (St. Pierre 2000; Tremain 2001; 2015).

My participants' view of autism as central to their identity is similar to Bertilsdotter-Rosqvist's finding where participants saw Asperger's as an identity more than a disability, as well as Brownlow and O'Dell's finding that autistic people viewed autism and Asperger's positively and did not want to be neurotypical (Brownlow and O'Dell 2006; Bertilsdotter-Rosqvist 2012). My findings differ from previous research demonstrating that people did not want to be seen as disabled, wanted to avoid being seen as autistic, and rejected aspects of being autistic in their identities (Baines 2012; Jones et al. 2015). While my participants are upset about being misunderstood by others around their autistic identities and traits, they seem to view this as a problem caused by people not understanding them, rather than caused by their autism. Their views about this may be partly caused by the influence of the neurodiversity movement and constitution of their subjectivities within this counter discourse. Mogensen and Mason found that how individuals received their diagnosis, including at what age and who they were told by, influenced how they viewed their autism and whether they saw it as part of their identity (Mogensen and Mason 2015). My research also supports this finding, as participants' views about their diagnosis are contextual.

## LIFE COURSE

The importance of context in how my participants have felt about their diagnosis over time supports Mogensen and Mason's findings where their participants felt differently about their diagnosis based on when in their lives they were diagnosed (Mogensen and Mason 2015). This also relates to previous discussion of the confusion and difficult feelings people go through if they spend most of their lives not knowing (Huws and Jones 2008; Mogensen and Mason

2015). My research supports previous findings about people's changing identities over their lifetime and processes of better understanding themselves, as well as Huws and Jones' assertion that while receiving the diagnosis can be a negative experience for people at first, it can be helpful as an explanation and lead to constructing a positive sense of self (Huws and Jones 2008; Bertilsdotter-Rosqvist 2012). Post-structural theory on the shifting nature of subject positions is illustrated in the changes participants have gone through in their lives (Goodley 2007; St. Pierre 2000).

So far this discussion has focused on diagnosis within the theme of *Life Course*. The subtheme of *Language for Intelligibility* was not covered in previous research, but theoretically one can interpret the experience of not having the language to describe marginalization as a lack of available discourses. Post-structuralists assert that people draw from discourses to find meaning in their experiences, so being unable to make sense of experiences demonstrates lacking access to particular discourses (St. Pierre 2000). As participants learned about the neurodiversity movement, they were better able to understand their life experiences. The theme of *Internalizing Responsibility* was also not covered in previous research, although this theme is connected to previous findings demonstrating autistic people negatively viewing their autism after negative social interactions. These findings are significant as they point to internalized ableism. As discussed previously, this internalization reflects theory on discursive constitution and self-governing (Goodley 2007). My findings for the theme of *Internalizing Responsibility* are significant because they illustrate how disciplinary power operates in individuals' ideas about themselves (Goodley 2007). The subtheme of *Language to Talk about Oppression* demonstrates how discourses can be unavailable to people, making it difficult to describe their subject positions and experiences. This subtheme also illustrates the work people must undertake, when

they can access these discourses, to communicate with people coming from a different discursive location (St. Pierre 2000).

## LIMITATIONS AND FUTURE RESEARCH

My research illustrates theory in ways that support and build on previous literature. Considering the importance of highlighting autistic people's perspectives, there should be much more research with this community. It is crucial for this kind of research to take a narrative focus, because this creates space where people have opportunities to share their experiences and ideas. Intersectionality is important in studying autism as well and more research should be conducted with autistic people who are people of colour, women, and LGBTQ, to look at diversity in autistic people's experiences. I am very interested in gender non-conformity and gender expression among autistic people, which would especially be interesting to look at because studies have found autistic people are more likely to be gender non-conforming, as Jack writes in her article on autism and gender (Jack 2012). Due to space limitations, I could not address gender in my research for this thesis, but it would be interesting for future research to look at autistic people's experiences and perspectives about gender.

I also think future research should explore the counter discourse of neurodiversity and how it constitutes the subjectivities of autistic and other mentally or neurologically disabled people. I touched on this briefly in this thesis, but as there is so much to discuss about autistic people, space limitations prevented me from focusing on neurodiversity. Only a small amount of research has looked specifically at the neurodiversity activist movement and at the subject position of "being neurodiverse." This is a growing movement, as my findings demonstrate, and research on this is needed.

An important question came up in interviews that is connected to the themes of *Diagnosis, Intelligibility, and Identity*: When is autism a diagnosis and when is it an identity? This question came up in regards to *Sarah* and *Rachel's* strong feelings about being autistic and their fears of a medical professional telling them otherwise, which in their view would take that identity away. The issue here of people's experiences not always being represented by diagnoses should be researched in more depth. An issue I explored in my interviews, but did not have space to address in this thesis was around autistic people's views about conformity and non-conformity. Through this I sought to explore how people experience "disciplinary power" in their lives and ways in which they resist (St. Pierre 2000). I think this is an important topic that should be explored in future research with autistic people.

## IMPLICATIONS

My research builds on previous literature, with *Language to Talk about Oppression, Internalizing Responsibility, and Hopes and Fears for the Future* not having been significantly addressed in the previous literature. These findings reveal significant issues that autistic young people are negotiating around intelligibility and understanding, internalized ableism, as well as thoughts and concerns about their lives and futures. Participants are thinking about and negotiating these issues in the context of how their subjectivities are constituted within discourses of autism.

My research is also important because it highlights the perspectives of autistic individuals in their 20s and includes the perspectives of people with self-diagnoses, groups that have been underrepresented in previous research on autism. Baines argues that studies focusing on autistic people's views have demonstrated the importance of this kind of research (Baines 2012). Mogensen and Mason argue that the majority of research on autism takes the perspective of the

medical model, focusing on deficits instead of more balanced representations of autistic people (Mogensen and Mason 2015). In 2008 Huws and Jones argued that autism research often excluded the perspectives of autistic people, instead focusing on people who cared for them, especially parents (Huws and Jones 2008). Notably, when I conducted my literature review, a significant amount of the articles I found centred on parents. There is also a lack of research with people diagnosed as adults as well as those who are self-diagnosed (Lewis 2016).

Regarding aspects of autistic identity, Mogensen and Mason assert there has been a lack of research on how young people are affected by the experience of receiving a diagnosis and how they view their diagnosis (Mogensen and Mason 2015). Ultimately, my research is significant in that it highlights perspectives that often go unheard. As McGuire argues, autistic people's narratives can be part of counter discourses of autism, and through highlighting these perspectives we can broaden ways of thinking about and understanding autism and autistic people's experiences (McGuire 2016). As I have illustrated here, autistic people's experiences and perspectives have been underrepresented in research, especially autistic people who are self-diagnosed. Furthermore, a focus on the deficit centred view of autism in research leads to underrepresentation of counter discursive autistic perspectives. By focusing on the experiences of four young people, whether or not they have a formal diagnosis, my research can increase understanding of autistic people's experiences and views.

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## Appendix A: Interview Guide

Tell me about when you first realized you were autistic.

How did you find out?

How did finding out make you feel?

Tell me about being autistic now.

In what ways do you identify as autistic and/or feel like this has been a label given to you?

In what ways have your feelings changed or stayed the same since you first found out?

Tell me about any other identities you would use to describe yourself.

In what ways are these connected to or different from your autistic identity/label?

How does the term “autistic” make you feel?

What do you associate with this term?

What do you know about the term “neurodiversity”?

What do you associate with this term?

In what ways is “neurodiversity” similar or different from “autistic”?

In what ways would you use or choose not to use these terms when talking about yourself?

Tell me about any other terms you know of and/or use.

In what ways have you heard them used by other people? (Friends? Family? Teachers? Employers? Medical professionals? Therapists?)

What do “conformity” and “non-conformity” mean to you?

What do you associate with these terms?

In what ways would you use them when talking about yourself and/or other people?

How do you talk to other people about your autistic identity/label?

Friends? Family? Teachers? Employers? Medical professionals? Therapists?

How have other people responded to your diagnosis/identification as autistic?

Friends? Family? Teachers? Employers? Medical professionals? Therapists?

Describe any changes over time or in different areas of your life. (Have things gotten better, worse, or stayed the same?)

What are your experiences of being misunderstood? (This could include your other identities besides autism)

When do people misunderstand you? (What places, contexts, and times?)

Who doesn't understand you?

How does being misunderstood feel?

Do you experience misunderstanding around some identities more than others? If so, which ones?

Describe any changes over time or in different areas of your life. (Have things gotten better, worse, or stayed the same?)

What are your experiences of being understood?

When do people understand you? (What places, contexts, and times?)

Who understands you? (This could include people as well as animals or pets)

Who do you think hypothetically would understand you? (Such as famous people you don't directly know, fictional characters, historical figures, etc.)

How does being understood feel?

Describe any changes over time or in different areas of your life. (Have you felt more understood at different times than others?)

How do you want other people to see you? (Tell me about unique/good/important things about yourself that you wish other people could see or understand.)

Tell me if there is anything else you would like to say.

## Appendix B: Letter of Invitation



### Narrative Study of Autism and Identity

My name is Hannah Monroe, and I am a Master's student in Critical Sociology at Brock University conducting research on the lived experiences of autistic people through semi-structured interviews. The purpose of this research is to learn about autistic people's identities as well as their views about autism and neurodiversity.

#### To participate:

- You must be 18-30 years of age.
- You must have been labeled as autistic at some point in your life, either by yourself through a self-diagnosis or by a medical professional.
- You must be able to provide detailed descriptions of your experiences (either verbally or in writing/typing.)
- You must be able to attend the interview independently. Sensory objects will be allowed.

If you are more comfortable typing your responses than talking, I can conduct the interview over email or you can type responses during an in person interview. Fidget toys, music, and ear plugs will be provided for in person interviews.

Interviews will take approximately 1 hour and 30 minutes. They will be semi-structured so that you can talk as much about any question as you wish and contribute any additional information that you feel is important. Interviews will be supportive and encouraging of your identities, experiences, and beliefs. You may choose the form of interviewing (such as in person, Skype, or email). For in person and Skype interviews, you will be able to select the location, keeping in mind privacy. You will also have the opportunity to look over your interview after it is transcribed and make any changes you feel will better represent your ideas.

#### Participants will be asked about:

- Ideas about autism and neurodiversity
- Views about conformity and non-conformity
- Experiences of forming identities
- Feelings of being understood or misunderstood
- Changes in experiences, at different times and around different people

For participating you will receive a \$10 gift card to Tim Hortons or a similar coffee shop.

**If you would like to participate, please note that if you interact with this post (e.g. liking or commenting), the privacy and confidentiality of your participation may be compromised.**

This research has received clearance from the Brock University research ethics board:

Brock University REB File #: 16-001 – NEWMAYER

**If you are interested in participating, please email me: [hm15gr@brocku.ca](mailto:hm15gr@brocku.ca)**

**Full contact information:**

- Hannah Monroe- MA Student, Department of Sociology, Brock University (Student investigator):  
Email: [hm15gr@brocku.ca](mailto:hm15gr@brocku.ca)
- Dr. Trent Newmeyer- Department of Women's and Gender Studies, Brock University (Supervisor):  
Email: [newmeyer@brocku.ca](mailto:newmeyer@brocku.ca)  
Phone: 905-688-5550 Ext 5118



## Appendix C: Letter of Consent

Date: July 3, 2016

Project Title:

Non-Conforming Subjectivities: The Use of Dominant and Counter Discourses in Narratives of Neurodiversity

Principal Investigator (PI): Trent Newmeyer, Faculty  
Department of Women's and Gender Studies  
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Student Principal Investigator (SPI):  
Hannah Monroe, MA student  
Department of Sociology  
Brock University

### INVITATION

You are invited to participate in a study that involves research. The purpose of this research is to learn about autistic peoples' identities and how they think autism is viewed in culture. Research will also explore whether individuals feel their identities and beliefs are understood by others.

### WHAT'S INVOLVED

As a participant, you will be asked to answer semi-structured questions about your identity, beliefs, and experiences associated with autism in a narrative interview. The interview will take approximately 1 hour of your time and interviews will take place in person, over Skype, or by email. You may choose the location of in person interviews. Interviews will be audio recorded so that they can be accurately transcribed. Interviews will take place at a time that is convenient for you, within a month after you agree to be interviewed. If you choose to be interviewed by email, you will have two weeks to respond to the interview questions.

### POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include having an opportunity to express your feelings and beliefs about your identity in a supportive environment, including discussing any thoughts or concerns you want to express, but may not have had a chance to. You will also receive a \$10 gift card to Tim Hortons.

In addition to benefits to you as a participant, this research could be beneficial for the autistic community. Your narrative could shed light on the experiences of autistic individuals, providing perspectives that could help dispel stereotypes of this community.

There also may be risks associated with participation. As research will explore personal experiences of a disability identification, you could potentially experience emotional distress from recounting experiences of misunderstanding and forms of discrimination. In order to minimize this risk, interviews will be semi-structured so that you can lead the conversation, sharing as much or as little of your experiences as you feel comfortable discussing. You will be provided with information about counseling helplines in case you experience emotional distress.

### CONFIDENTIALITY

You will have a pseudonym throughout the research and in the release of findings. The information you provide will be kept confidential. Your name will not appear in any thesis or report resulting from this study. However, with your permission, anonymous quotations may be used. I will remove any identifiers from transcripts so that people will not be able to recognize you from looking at findings. You will also be able to remove information that could identify you.

Within one week after the interview has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. This transcript will contain personal details from your interview, so be sure it keep it secure. You will then have two weeks to review your transcript and email it back to me. Reviewing your transcript should take approximately 1-2 hours.

Data collected during this study will be stored in a locked file cabinet or kept on my computer and password protected. After conducting interviews, recordings will be kept on my phone and password protected. Data will be kept until this project is completed, August 2017, after which time I will destroy documents through deleting digital copies and shredding any written records.

Access to this data will be restricted to Hannah Monroe and Trent Newmeyer. If we conduct the interview in your home, there are limits to privacy and confidentiality due to mandatory reporting laws that require the researcher to report suspected abuse or neglect.

### **VOLUNTARY PARTICIPATION**

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled.

### **PUBLICATION OF RESULTS**

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available. To see the findings from this research, you can contact Hannah Monroe ([hm15gr@brocku.ca](mailto:hm15gr@brocku.ca)). Feedback will be available in August 2017.

### **CONTACT INFORMATION AND ETHICS CLEARANCE**

If you have any questions about this study or require further information, please contact Trent Newmeyer or Hannah Monroe using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University - 16-001 - NEWMEYER. If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, [reb@brocku.ca](mailto:reb@brocku.ca).

Thank you for your assistance in this project. Please keep a copy of this form for your records.


### **CONSENT FORM**

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Appendix D: Clearance from Ethics

|   |                             |  |
|---|-----------------------------|--|
|  | <b>Brock University</b>     |  |
|   | Research Ethics Office      |  |
|   | Tel: 905-688-5550 ext. 3035 |  |
|   | Email: reb@brocku.ca        |  |

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Social Science Research Ethics Board

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**Certificate of Ethics Clearance for Human Participant Research**

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|                         |   |             |                |
|-------------------------|---|-------------|----------------|
| DATE:                   | 9/12/2016   |             |                |
| PRINCIPAL INVESTIGATOR: | NEWMEYER, Trent - Recreation & Leisure Studies  |             |                |
| FILE:                   | 16-001 - NEWMEYER   |             |                |
| TYPE:                   | Masters Thesis/Project  | STUDENT:    | Hannah Monroe  |
|                         |   | SUPERVISOR: | Trent Newmeyer |
| TITLE:                  | Non-Conforming Subjectivities: The Use of Dominant and Counter Discourses in Narratives of Neurodiversity |             |                |

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**ETHICS CLEARANCE GRANTED**

|                        |                        |
|------------------------|------------------------|
| Type of Clearance: NEW | Expiry Date: 9/29/2017 |
|------------------------|------------------------|

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The Brock University Social Science Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 9/12/2016 to 9/29/2017.

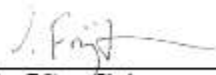
The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 9/29/2017. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <http://www.brocku.ca/research/policies-and-forms/research-forms>.

In addition, throughout your research, you must report promptly to the REB:

- Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- New information that may adversely affect the safety of the participants or the conduct of the study;
- Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:   
 Jan Frijters, Chair  
 Social Science Research Ethics Board

**Note:** Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.